

# Review of palliative care services in Scotland

Report supplement: Survey of bereaved families and friends



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# Part 1. Summary

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 George Street Research to carry out a survey of bereaved families and friends. This supplement accompanies the national report and summarises the main findings from that survey.

## Methods

2. George Street Research carried out a postal, self completion survey of people who had recorded a death of someone who died between 12th March 2007 and 16th September 2007. The methodology was based on the VOICES approach, developed by Addington-Hall et al.<sup>1</sup> The sample areas were NHS Greater Glasgow and Clyde, NHS Highland, NHS Borders and NHS Fife. Nine hundred and ninety-seven responses were received and analysed.

## People included in the survey

3. The sample included family and friends of people who died of cancer (35 per cent) organ failure (50 per cent), neurological conditions (10 per cent) and other conditions (4 per cent).<sup>2</sup> It included the family and friends of people who died in hospital (52 per cent), nursing or residential homes (20 per cent), at home (18 per cent), hospices (8 per cent) and in the home of a family member or friend (1 per cent).

## Care settings

### Home

4. Just over half of the people that died received some care at home in the last three months of their life. Sixty-two per cent received care from a district or community nurse, 53 per cent from a home care worker or home help and 24 per cent from a Macmillan or hospice nurse. Over half (54 per cent) received as much help as they needed from health services and 42 per cent as much help as they needed from social services, but getting access to help presented some problems for 30 per cent. Two thirds of patients were offered a Community Care Assessment while a quarter of carers were offered a Carers Assessment.

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<sup>1</sup> A randomised controlled trial of postal versus interviewer administration of a questionnaire measuring satisfaction with, and use of, services received in the year before death. Addington-Hall J, Walker L, Jones C, Karlsen S and McCarthy M J Epidemiological Community Health, 1998; 52: 802-807. Known as VOICES.

<sup>2</sup> Due to rounding, the percentages do not always sum to 100.

## Residential or nursing home

5. Thirty percent of those that died received care in a nursing or residential home during the last three months of their life. This proportion was highest amongst those who were over 75 when they died (37 per cent), people who died of a neurological condition (62 per cent) and women (33 per cent). Fifty-seven percent of carers reported no problem in accessing such care.

## Hospital

6. Seventy-two percent of those that died had a hospital stay of more than 24 hours in the last three months of their life. This proportion was highest amongst people who died in a hospice (81 per cent), men (79 per cent) and people who died of cancer (78 per cent). Over half of the carers of people who had a hospital stay in the last three months (57 per cent) were involved as much as they wanted to be in decisions about care and treatment but 35 per cent would have liked to be more involved.

## Hospice

7. Eleven percent of the people that died spent more than 24 hours in a hospice in the last three months of their life. This proportion was highest amongst people in Fife (17 per cent), younger age groups (34 per cent of under 55s, 22 per cent of 55-74 year olds) and people who died of cancer (28 per cent).

## Care needs

### Personal care needs

8. The extent to which personal care needs were met varied across settings (92 per cent of carers of people who spent time in a hospice report these needs being met, compared with 78 per cent in nursing or residential homes and 66 per cent in a hospital). In home settings, most carers reported that personal care needs were met by health and social services, though the proportions reporting this were higher amongst those caring for people who were older or who died of neurological conditions. In the last three days of life, 80 per cent of carers reported that there was enough help with personal care needs and 77 per cent said there was enough help with nursing care.

## Treatment of pain

9. The majority of those that died had treatment for pain, although the percentage was higher amongst people who died of cancer. There were variations across NHS board and care settings:
  - the highest proportions of those reporting effective relief of pain were where this treatment was received in a hospice

- the highest proportions reporting that the treatment was only partially effective or not effective were where this treatment was received at home
- for people who died of organ failure, pain relief was perceived to have been less effective than for people with other conditions regardless of where the care was provided.

## Communication

10. The extent to which carers could discuss their worries or fears with care staff as much as they wanted varied across care settings, cause of death, condition of the patient, age of the person that died and socio-demographic group. Seventy-three per cent of carers reported that they could discuss their worries with hospice staff compared to only 51 per cent who reported that they could discuss worries with hospital staff.
11. The majority of carers dealing with hospital or hospice staff found their explanations about the condition or treatment of the person that died easy or fairly easy to understand (73 per cent for hospital and 89 per cent for hospice staff). The majority of carers dealing with a visiting GP (78 per cent) or with nursing home staff (84 per cent) felt that these people had time to listen and discuss issues with them.

## Respite care

12. Just over half of the sample (55 per cent) did not ask for respite care, because they did not think they needed this kind of help and 7 per cent were unaware this might be available. Ten percent of the carers asked for respite care. However, 22 per cent of carers who asked for respite care did not get it and a further 17 per cent who asked for respite care had to wait to get it.

## Out-of-hours services

13. Out-of-hours services had been contacted at least once in the last three months of life for 53 per cent of the people that died. This proportion was highest amongst people who died in a hospice, people who died at home, people who died of cancer and younger age groups. Methods of contacting services were:
  - 64 per cent contacted NHS 24
  - 39 per cent contacted a GP
  - 21 per cent dialled 999
  - 19 per cent contacted community nurses
  - only small proportions had contacted any other out-of-hours service.

## Care at the end of life

14. During the last three days of life, 46 per cent of the people that died spent most of their time in a hospital, 24 per cent at home and 21 per cent in a nursing or residential home. Sixty-nine percent of carers were involved as much as they wanted to be in decisions about treatment and care during this time. The majority (77 per cent) said there was enough help with nursing care during this time although this proportion was higher amongst those caring for people who were in a hospice, nursing or residential home than for those caring for someone who was in hospital or at home.
15. Eighty-one percent of carers believed that the person they cared for died in the right place. Where carers thought the person they cared for had not died in the right place, this was usually because it was not where the person wanted to die, though a quarter said it was because the care was poor where the person died. Twenty-five percent of carers thought that health services could have made the end of life easier and 15 per cent thought that social services could have done so.
16. Fifty-seven percent of carers reported no difficulty in meeting the cost of care and a further 23 per cent not much difficulty.

# Part 2. Introduction

17. 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 the review, George Street Research was commissioned to conduct a self-completion postal survey of informal carers of people with palliative care needs<sup>3</sup>. This supplement accompanies the national report and summarises the main findings from that survey.

## Context

### Palliative care

18. Palliative care embraces many elements of supportive care, and has been defined by the World Health Organisation (WHO) as: *“An approach that improves the quality of life of patients and their families facing the problems associated with life-threatening illness, through the prevention and relief of suffering by means of early identification and impeccable assessment and treatment of pain and other problems, physical, psychosocial and spiritual.”*<sup>4</sup>

19. According to the Scottish Partnership for Palliative Care everyone suffering from an incurable progressive illness should receive palliative care.<sup>5</sup> Historically, palliative care developed mainly for people with cancer but it is now recognised that it can also help those with other conditions, for example, advanced heart failure, dementia or motor neurone disease. People of all ages can benefit from palliative care. It can help at all stages of the illness from diagnosis onwards, while treatment is in progress and at the end of life. Palliative care aims to maintain and, as far as possible, improve quality of life for patients and their families. Palliative care is about:

- controlling pain and other distressing symptoms
- helping patients and families cope with the emotional upset and practical problems of the situation
- helping people to deal with spiritual questions which may arise from their illness
- supporting families and friends in their bereavement.

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<sup>3</sup> Informal carers, for the purposes of this survey, are people who care for someone, or are responsible for arranging for their care, on an unpaid basis - often a family member or spouse.

<sup>4</sup> <http://www.who.int/cancer/palliative/definition/en/>

<sup>5</sup> <http://www.palliativecarescotland.org.uk/pallcare/index.htm>

20. Palliative care can be provided by generalist staff such as GPs, district nurses and other hospital or community staff who are not specialists in palliative care, and by specialist palliative care doctors, nurses and other staff working in hospitals, hospices and in the community.

## Aims and objectives

21. The informal carers survey was designed to assess:
- the extent to which people with palliative care needs are receiving palliative care services, and from which providers (hospital, hospice, nursing or residential home, community services)
  - informal carers' experiences and views of the local delivery of palliative care, including:
    - choice of appropriate place of care
    - information and communication from service providers
    - access to and referral between services, including out-of-hours
  - the extent to which local palliative care services meet patients' needs, including:
    - how well they address physical needs
    - how well they address emotional needs
    - how well they address spiritual needs.

## Methodology

22. In order to assess the views, experiences and perceptions of palliative care services and provision, a self-completion questionnaire was distributed five months or more after bereavement to the person who registered a death.
23. This methodology has been successfully used by others to look at the provision of palliative care services.<sup>6 7</sup> In 1999 Jacoby et al carried out a methodological assessment into the feasibility of using postal questionnaires to examine carer satisfaction with palliative care. The authors concluded that postal approaches represent an acceptable means of assessing user satisfaction with palliative care, compared with more resource-intensive methods such as face-to-face

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<sup>6</sup> *Feasibility of using postal questionnaires to examine carer satisfaction with palliative care: a methodological assessment*, Jacoby A, Lecouturier J, Bradshaw C, Lovel T and Eccles M, *Palliative Medicine* 1999; 13: 285-298.

<sup>7</sup> *A randomised controlled trial of postal versus interviewer administration of a questionnaire measuring satisfaction with, and use of, services received in the year before death*, Addington-Hall J, Walker L, Jones C, Karlsen S and McCarthy M J *Epidemiological Community Health*, 1998; 52: 802-807. Known as VOICES.



interviews. Indeed, in a different study conducted by Addington-Hall et al (1998) (known as **VOICES**) the authors concluded that postal questionnaires are an acceptable alternative to interviews in retrospective post-bereavement surveys of care for people who are dying.

## Sampling

24. The sample for this survey was provided by the General Register Office for Scotland (GROS). The methodology did not need approval by an NHS Ethics Committee since it did not involve contact with patients or their medical records. However, GROS Privacy Advisory Committee approval was obtained and GROS actively contributed to developing the approach to informal carers. The initial approach letter came from GROS to maintain confidentiality and comply with data protection legislation.
  
25. The sample was drawn by GROS from the Scottish register of deaths. The inclusion criteria were:
  - adults aged over 18 who died between 5 and 11 months before the survey (ie between 12<sup>th</sup> March 2007 and 16<sup>th</sup> September 2007)
  - deaths registered in four sample NHS boards: Borders, Fife, Greater Glasgow and Clyde, Highland
  - the primary or secondary cause of death was a condition which would potentially have benefited from palliative care:
    - certain infectious and parasitic diseases
    - neoplasms
    - diseases of the blood and blood-forming organs and certain disorders involving the immune mechanism
    - endocrine, nutritional and metabolic diseases
    - mental and behavioural disorders
    - diseases of the nervous system
    - diseases of the eye and adnexa
    - diseases of the ear and mastoid process
    - diseases of the circulatory system
    - diseases of the respiratory system
    - diseases of the digestive system
    - diseases of the skin and subcutaneous tissue

- diseases of the musculoskeletal system and connective tissue
- diseases of the genitourinary system
- from this sample we excluded:
  - all cases where the name of the person who registered the death was incomplete
  - all cases where the person who registered the death was not a relative, friend, acquaintance etc (eg police, funeral directors, solicitors)
  - all cases where the deceased was not a resident of Scotland
  - all deaths with an external cause (accidents, suicides, homicides, etc.) as the underlying cause
  - all deaths coded as drug/substance abuse
  - all deaths coded to ill-defined and unknown causes of mortality.

26. Our final sample, within these criteria, included all deaths registered in the six month period in NHS Borders (557) and NHS Highland (1,475) and a random sample of 1,500 registered deaths in each of NHS Fife and NHS Greater Glasgow and Clyde. In NHS Fife and NHS Greater Glasgow and Clyde, where the numbers permitted, GROS provided some 'oversample'.<sup>8</sup>

## Data collection

27. Due to the sensitive nature of this study, there were a number of stages involved in collecting the data. These included:
- a letter from the GROS to all potential respondents (informal carers) in the sample, informing them of the nature of the study and providing them with the opportunity to 'opt-in' (ie to agree to take part) by returning a reply slip. A copy of this letter is provided in **Appendix 1**.
  - a questionnaire, covering letter and reply paid envelope were sent to all those who opted-in
  - in NHS Greater Glasgow and Clyde, where response rates were lower throughout, we tried to increase the response rate by sending an extra 217 letters to the 'oversample' and sending a reminder to those who had opted-in but where no response had been received.

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<sup>8</sup> Oversample is additional cases over the specified sample, that could be used in the event of poor response rates or invalid cases.

28. Exhibit 1 details the numbers of letters distributed as well as the numbers and response rates for those who opted-in and those who returned the questionnaires.

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## Exhibit 1

### Final sample numbers and response rates

	TOTAL	Fife	Borders	Greater Glasgow & Clyde	Highland
Letters sent out	5,249	1,500	557	1,717	1,475
Total opt-in	1,289	409	143	332	405
Opted-in % of total	24.6	27.3	25.7	19.3	27.5
Returned questionnaires	997	311	116	268	302
Returned % of opted-in	77.3	76.0	81.1	80.7	74.6
Returned % of total	19.0	20.7	20.8	15.6	20.5

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## Questionnaire

29. The questionnaire that was used was based on the VOICES questionnaire, but much reduced in length to cover only the issues of particular interest to this survey. The questionnaire was subject to a brief informal pilot (amongst recently bereaved volunteers known to the research team) and amended following a pilot debrief.
30. Questionnaires were personalised to account for the gender of the deceased, ie a male and a female version. Each questionnaire was distributed with a covering letter and reply paid envelope. Copies of the covering letter and questionnaire are included in **Appendices 2** and **3**.

## Socio-economic group

31. In order to classify the person that died into a socio-economic group, George Street Research used CACI Ltd to apply ACORN geodemographic codes to the data. ACORN combines geography with demographics and lifestyle information, to create a tool for understanding the different types of people in different areas throughout the country.<sup>9</sup> George Street Research provided CACI with the postcode of the person that died and CACI provided ACORN categories based on socio-demographic and geographical attributes. These are:

- wealthy achievers
- urban prosperity

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<sup>9</sup> <http://www.caci.co.uk/pdfs/Acorn%20Guide.pdf>

- comfortably off
- moderate means
- hard pressed

**Appendix 4** provides a more in-depth description of each of these categories as defined by CACI.

## People included in the survey

32. A total of 997 questionnaires were completed by carers. Exhibit 2 provides a profile of the sample of people who died.

### Exhibit 2

#### Profile of the sample of people who died

	Percent of all who died <sup>1</sup>		Percent of all who died <sup>1</sup>
<b>NHS board</b>		<b>Cause of death<sup>2</sup></b>	
Fife	31	Cancer	35
Highland	30	All organ failure	50
Greater Glasgow and Clyde	27	All neurological conditions	10
Borders	12	Other	4
<b>Gender</b>		<b>Location of death</b>	
Male	41	Hospital	52
Female	59	Nursing or residential home	20
		At home	18
<b>Age range</b>		Hospice	8
18-34	0	In home of family member or friend	1
35-54	4		
55-74	22	<b>ACORN category</b>	
75+	74	1 Wealthy achievers	25
		2 Comfortably off	19
		3 Urban prosperity	11
		4 Moderate means	9
		5 Hard pressed	34
		Unclassified	2 <sup>3</sup>
	Total = 997		Total = 997

<sup>1</sup> Does not always add to 100% due to rounding.

<sup>2</sup> Cause of death classifications were provided by GROS and grouped by Audit Scotland (see **Appendix 5**).

<sup>3</sup> Post code does not exist, it is a business post code, or a communal establishment eg prison, hospital or nursing home. ACORN categories are discussed further in paragraph 31.

33. Exhibits 3 to 7 look at how these variables relate to each other and provide context for the analysis.

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### Exhibit 3

#### Age at death by gender

Age at death	% of total (997)	Gender	
		Female (404) %	Male (593) %
18-54	4	-	5
55-74	22	17	30
75+	74	79	65

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### Exhibit 4

#### Age at death by cause of death

Age at death	% of total (997)	Cause of death (%)		
		Cancer (352)	All organ failure (502)	All neurological conditions (104)
18-54	4	7	2	5
55-74	22	39	12	17
75+	74	55	86	78

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### Exhibit 5

#### Gender by cause of death

Gender	% of total (997)	Cause of death (%)		
		Cancer (352)	All organ failure (502)	All neurological conditions (104)
Male	41	49	35	38
Female	59	51	65	62

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## Exhibit 6

### Age at death by location of death

Age at death	% of total (997)	Location of death (%)			
		At home (181)	Hospital (514)	Hospice (78)	Nursing / residential home (203)
18-54	4	7	4	13	-
55-74	22	34	22	46	4
75+	74	59	74	41	96

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## Exhibit 7

### Location of death by cause of death

Location of death	% of total (997)	Cause of death (%)		
		Cancer (352)	All organ failure (502)	All neurological conditions (104)
At home	18	28	15	10
Hospital	52	43	58	42
Hospice	8	21	1	-
Nursing/ residential home	20	8	25	46

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## Reporting the findings

### Views of carers

34. The remainder of the report presents the main findings from this survey. It should be borne in mind that the findings are based on the views of the carers of those who died (which are subjective), and are retrospective in nature. We have presented findings in relation to the whole sample throughout and where there are significant differences between sub-groups of the sample, these are discussed.

- **Part 3** presents findings relating to the different settings in which people received care and their informal carers' experiences and views on how easy these services were to access.
- **Part 4** presents the findings relating to the various needs - physical, emotional and spiritual - that patients and carers may have had during their illness and the extent to which their informal carers felt these were met.
- **Part 5** deals with out-of-hours services and respite care
- **Part 6** presents findings relating to the period surrounding the person's death.

## Quantitative data

35. Throughout the report, where there are statistically significant differences between subgroups (eg by NHS board, age, gender, location of death, cause of death, ACORN category), we have reported these. Statistical significance is based on standard errors for percentages at the 95 per cent confidence level. Where there were insufficient numbers within a subgroup to report findings with any confidence, we have not provided an analysis.
36. Percentages in charts do not always add to 100 per cent:
  - for some questions, multiple responses were allowed and so totals add to more than 100
  - for some questions, there were high levels of non-response, resulting in totals of less than 100.

## General comments

37. The final section of the questionnaire offered respondents an opportunity to provide any additional comments. This resulted in a wide range of comments, both positive and negative. Over half of respondents (55 per cent) commented, 13 per cent providing negative comments about care, staff or services in hospital, 11 per cent positive comments about care, staff or services in hospital and smaller proportions about other services and aspects of service.
38. It is beyond the scope of this report to analyse and present these comments in detail. However, we have included some examples throughout the following sections, for illustrative purposes.

# Part 3. Care settings

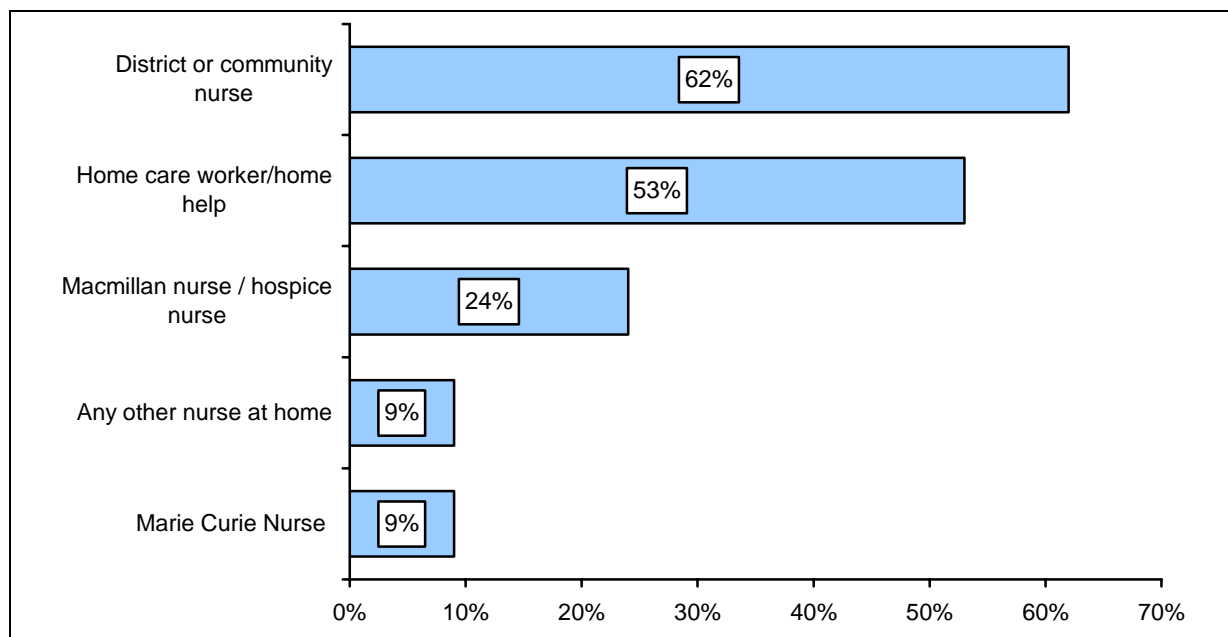
## Care at home

39. This section relates to the support the person that died received at home during the last three months of their life.
40. All respondents participating in the survey were asked to state whether, during the last three months of life, the person they cared for had a health problem for which they needed home care, such as assistance with home nursing, help with bathing or dressing, household tasks etc. In response to this question, just over half (56 per cent) indicated that the person they cared for needed care at home during this time. Sixteen per cent did not require home care and for around one in four (22 per cent) this was not applicable because the person they cared for was not at home during the last three months of their life (7 per cent did not answer this question).
41. The following analysis is based on the 56 per cent (554 respondents) who received care at home. People within the age range 55-74 when they died are more likely to have received care at home (71 per cent) than those over 75 (51 per cent). Those respondents who cared for someone who received help at home were asked about the services received (Exhibit 8)

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### Exhibit 8

**In the last three months of life, did the person you cared for receive any help at home from any of the services listed below?**



The figures are the percentage of all who received help at home in the last three months (554). Values below nine per cent are not presented.

Source: Question A2

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42. Age, location of death and cause of death are linked to the help received at home in the last three months of life:

- people aged 75+ were more likely to have received services from a home care worker, home care aide or home help (64 per cent) in comparison to those in the 18-54 (19 per cent) and 55-74 (32 per cent) age groups
- those who died at home or in a hospice were most likely to have received help from a district or community nurse (75 per cent and 79 per cent respectively) or from a Macmillan or hospice nurse (40 per cent and 57 per cent respectively)
- those who died of cancer were more likely than those with organ failure or neurological conditions to have received support from a district nurse, Marie Curie nurse, Macmillan nurse or hospice nurse. Patients with neurological conditions or organ failure were more likely than patients with cancer to receive support from a home carer.

43. Many respondents took the opportunity to provide additional comments on the quality of care services in the home.

*“I would have been unable to look after him at home without the support of the local GP and District Nurse”*

*“Good home care services enables us to look after him for as long as possible before he was admitted to hospital”*

*“The carers were kind and met all his needs”*

*“Some carers do not do their job properly”*

*“There should be more supervision of home care workers.”*

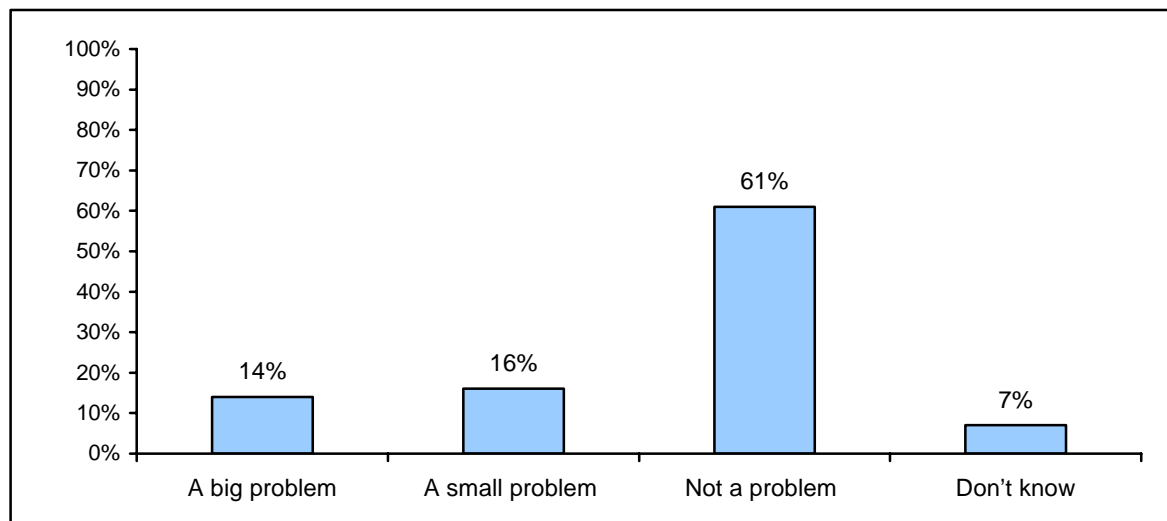
## Getting support at home

44. When asked how much of a problem it was getting help at home, the majority reported no problem (Exhibit 9).

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### Exhibit 9

**How much of a problem, if any, was it to get help at home from any of the services listed?**



The figures are the percentage of all who received help at home in last three months (554).

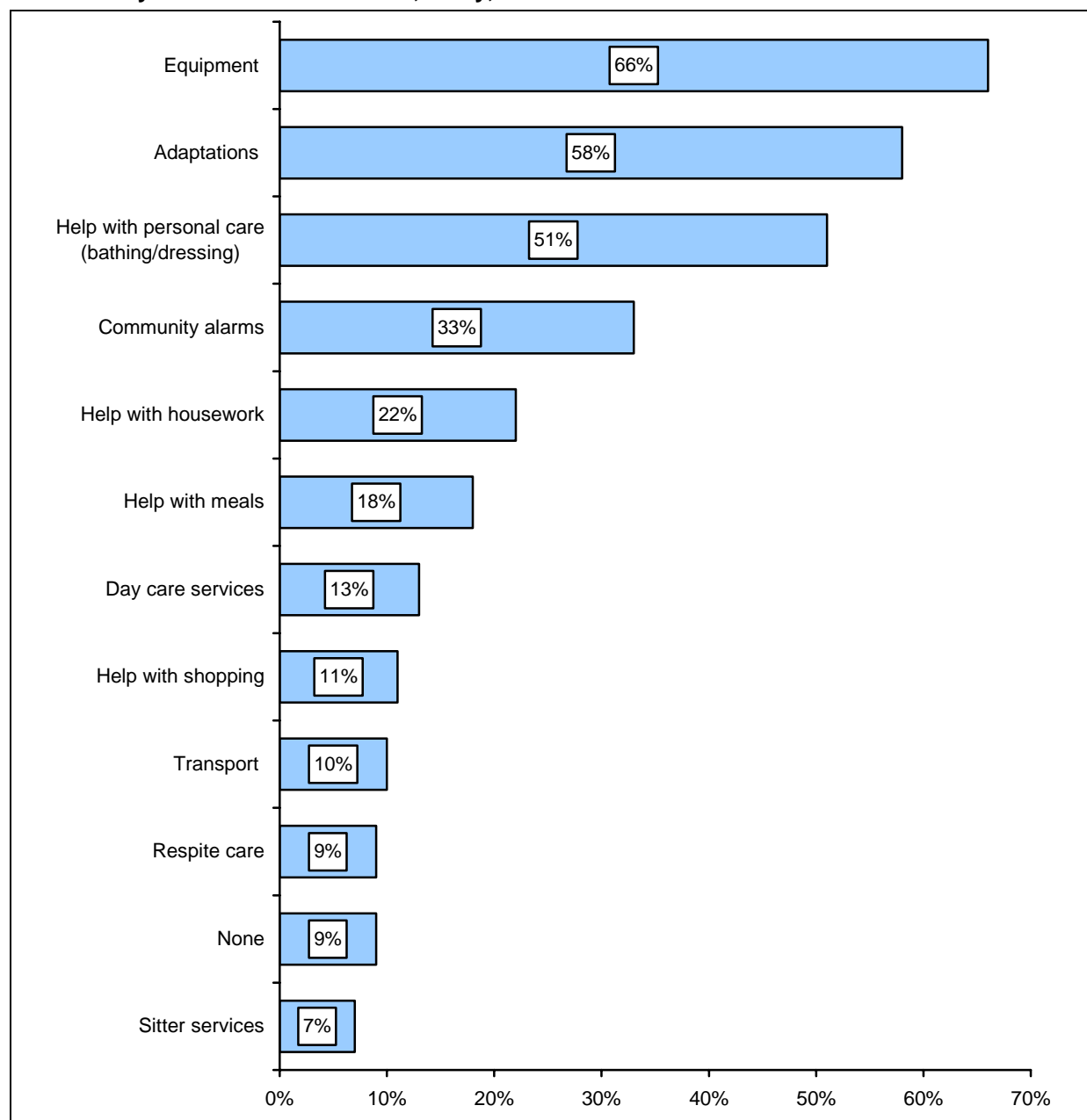
Source: Question A3

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45. All patients are entitled to an assessment of their needs in order to receive services and support at home – this is called a Community Care Assessment and may be undertaken by an occupational therapist or local social work department. Two thirds of respondents who provided information about someone who received care at home reported that a Community Care Assessment was offered, 21 per cent that it was not. This percentage varied by NHS board, from 77 per cent being offered an assessment in Fife to 51 per cent in Borders. Fifty-five per cent of carers of people aged 55-74 and 71 per cent of carers of people of 75+ reported that an assessment was offered.
46. Exhibit 10 shows the services received as a result of a Community Care Assessment by people who received care at home. The most commonly received services were equipment and adaptations.

## Exhibit 10

Please can you tell us what services, if any, he/she received?



The figures are the percentage of all who were offered a Community Care Assessment (367). Values below seven per cent are not presented.

Source: Question A5

47. Further analysis showed that:

- people in Borders were less likely to have received help with meals (8 per cent) than people in Fife (23 per cent)
- people in Highland were less likely to have received help with housework (15 per cent) than those in Fife (29 per cent)

- people in Fife were more likely to have received help with community alarms (47 per cent) than those in Greater Glasgow and Clyde (26 per cent) or Highland (27 per cent)
- twenty-seven per cent of women had help with housework, compared to 15 per cent of men
- men were more likely than women to have received day care services (17 per cent compared with 10 per cent)
- ninety-one per cent of those receiving help with meals were over 75 years old, as were 83 per cent of those receiving help with housework and 89 per cent of those receiving help with shopping
- eighty-four per cent of those receiving community alarms and 77 per cent of those receiving help with personal care were also over 75 years old
- those who died of neurological conditions were most likely to have received help with day care services (27 per cent), respite care (24 per cent), community alarms (43 per cent), personal care (73 per cent) and adaptations (78 per cent).

48. Some respondents provided additional comments in relation to these services:

*“Equipment and alarms were so easy to organise, communication between all concerned was excellent”*

*“I asked for equipment (a wheelchair) in January and the request was not approved until April”*

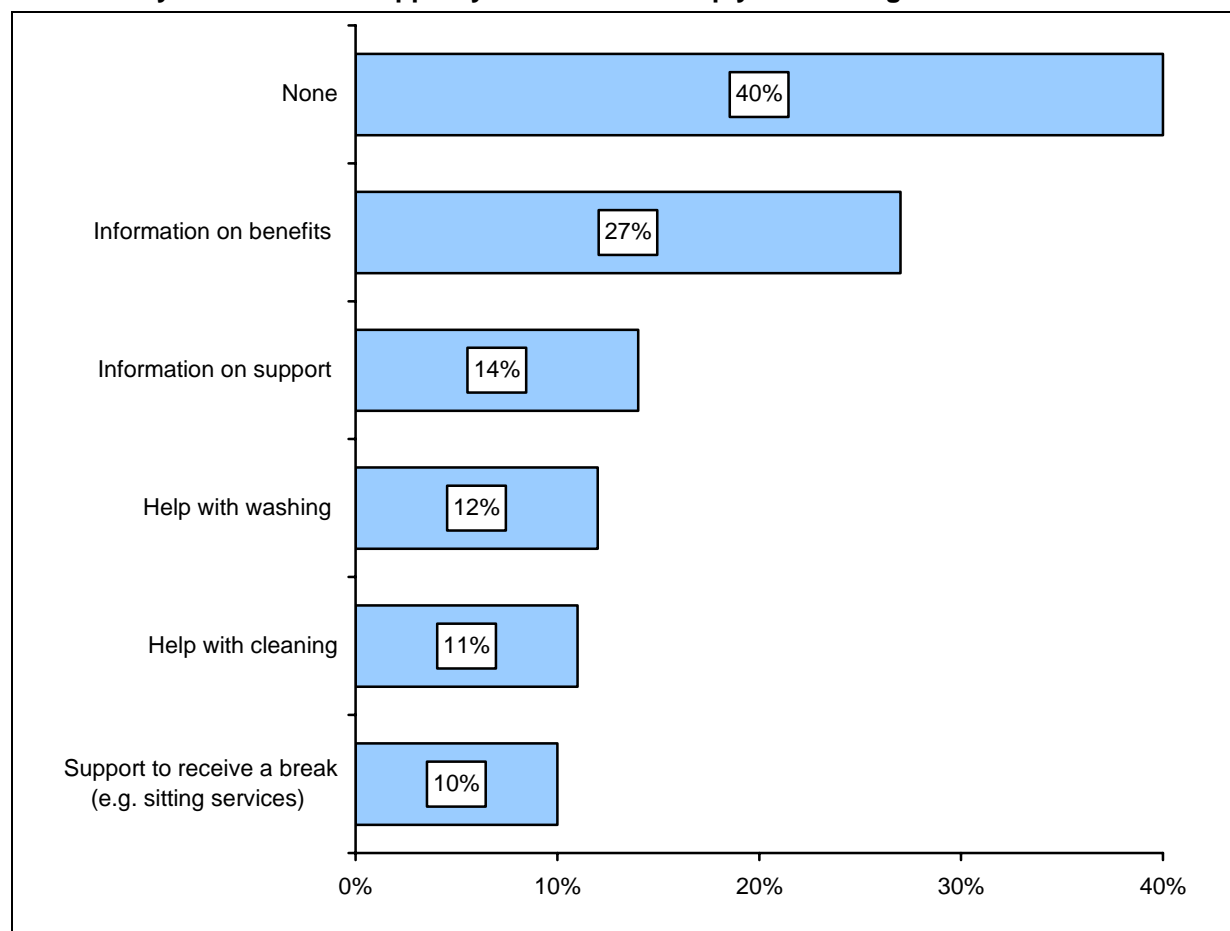
*“The equipment I asked for did not arrive until after his death”*

## Support for carers

49. Carers are eligible for a Carer’s Assessment, which assesses any needs they might have in their role as carer. A quarter (25 per cent) of respondents who had cared for someone at home reported that they were offered a Carer’s Assessment, 66 per cent were not and the remainder did not reply (3 per cent) or did not know (6 per cent).
50. Exhibit 11 shows the type of help, if any, received as a result of assessment.

## Exhibit 11

Please can you tell us what support you received to help you in caring for him/her?



The figures are the percentage of all who were offered a Carers' Assessment (140). Values below 10 per cent are not presented (only very small values).

Source: Question A10

51. Further analysis showed that:

- a quarter of respondents in Borders reported that they received no help compared to almost half (48 per cent) in Greater Glasgow and Clyde
- almost half (45 per cent) of the respondents in Borders received information on benefits they might be entitled to claim. This was almost double the percentage of respondents who received this support in the other areas (22 per cent in Fife, 25 per cent in Greater Glasgow and Clyde and 26 per cent in Highland).

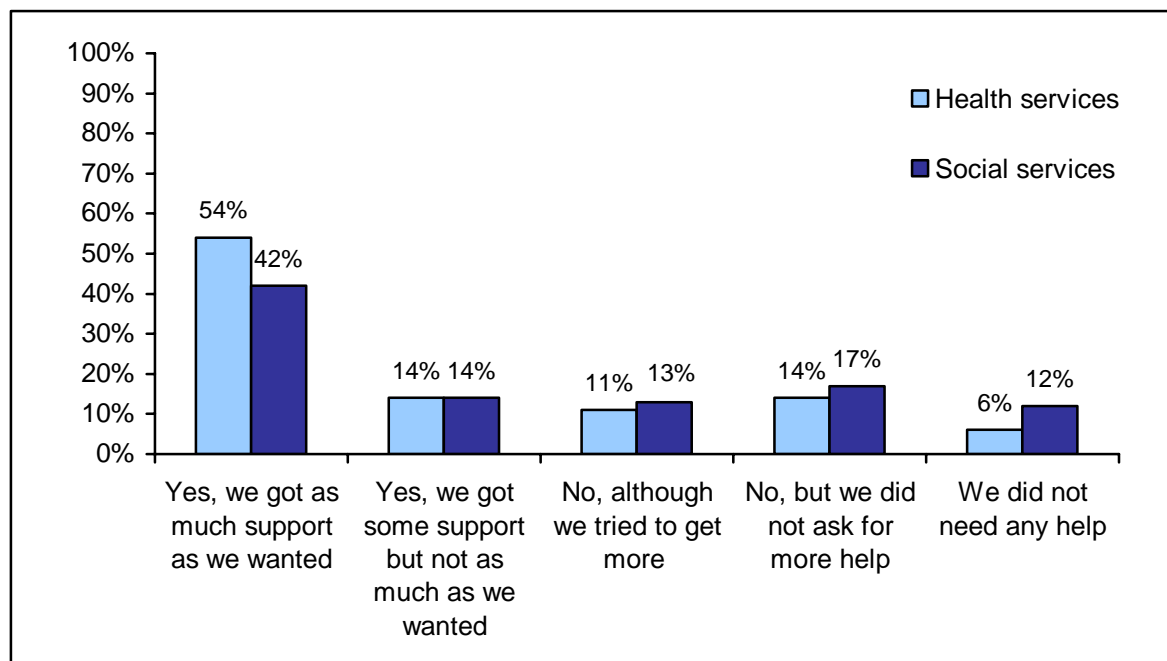
## Amount of support from health and social services

52. Respondents were asked whether or not they received as much help and support from (1) health services and (2) social services as they wanted. Exhibit 12 compares the results from each of these questions.

## Exhibit 12

**Overall, do you feel that you and your family got as much help and support from health services, such as nurses, as you wanted when caring for him/her?**

**Overall do you feel that you and your family got as much help and support from social services, such as home care workers, as you wanted when caring for him/her?**



The figures are the percentage of all who received help at home in the last three months (554).

Source: Questions A11 and A12

53. We found that:

- sixty-seven per cent of carers of people who died at home received as much help as they wanted from the health services
- sixty-two per cent of those in the wealthy achievers category received as much help as they wanted from health services, compared to 46 per cent in the hard pressed category
- carers of people who died of neurological conditions and cancer were more likely (70 per cent and 59 per cent respectively) to have received as much help from health services as they wanted than carers of people who died of organ failure (48 per cent)
- carers of women were more likely than carers of men to have received as much help from social services as they needed (47 per cent and 34 per cent respectively). Note that women were more likely than men to have received help as a result of their community care assessment.
- the older the person who died, the more likely their carer is to have reported that they received as much help as they wanted from social services – 23 per cent for the under 55 age group, rising to 47 per cent for those caring for people who were over 75. Note that older people were more likely to have received help as a result of their community care assessment.

54. Respondents provided additional comments on health and social services:

*“As a qualified District Nurse with 30 years experience, I have seen great changes in palliative and terminal care. It has become more patient-focussed”*

*“When we complained about the conditions in the nursing home the Health Board Inspectorate were very bad and rude to me. This put me off complaining again”*

*“Excellent service from Social Services”*

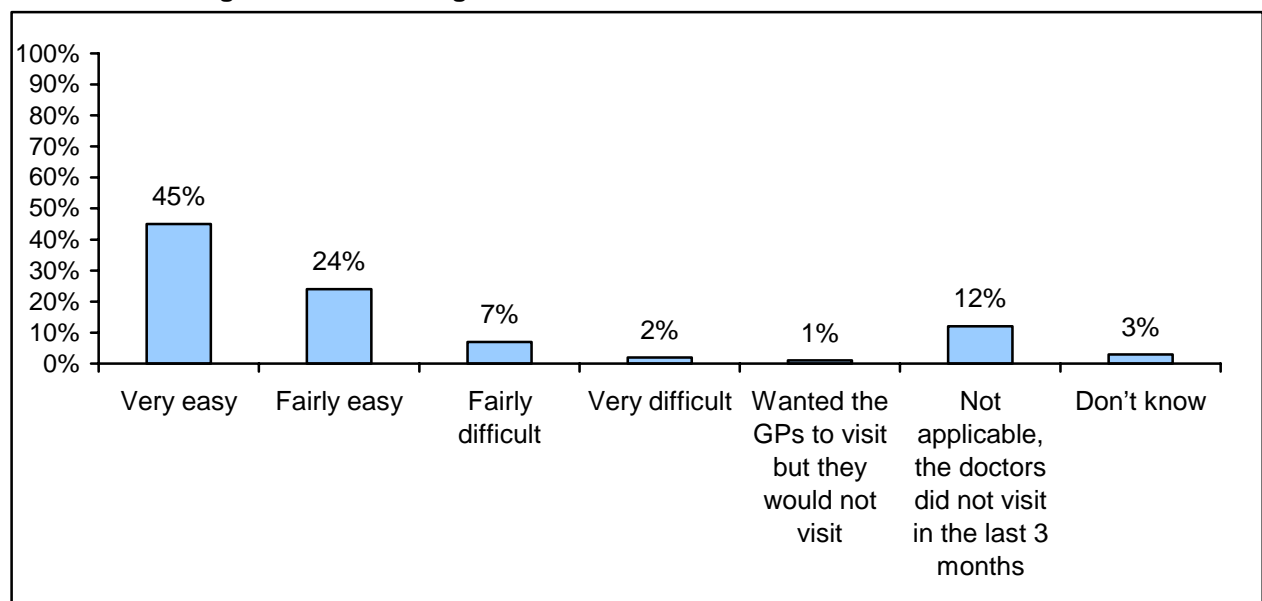
*“Social Services were a disgrace.”*

## Care from GPs

55. Respondents were asked how easy or difficult it was to get the doctor to agree to come to visit the person they cared for. This question specifically related to GPs who visited the patient at home, or in a nursing or residential home, in the last three months of their life. Seventy-eight percent answered this question with the highest proportion. Almost half of the respondents (45 per cent) reported that it was very easy to get the doctor to visit (Exhibit 13).

### Exhibit 13

**If the doctor visited the person you cared for in the last three months of life, how easy or difficult was it to get the doctor to agree to come and visit?**



The figures are the percentage of all respondents (997).

Source: Question B1

56. Fifty per cent of those caring for people in Highland said it was very easy to get a doctor to come and visit compared with 36 per cent of those caring for people in Greater Glasgow and Clyde. Seventy-three per cent of carers of wealthy achievers and 78 per cent of carers of people with cancer said that getting a doctor to visit was very or fairly easy.
57. Additional comments were made about GPs and the service they offer:

*“My family and I felt fully supported by our GP”*

*“The GP and first hospital treated him badly, they did not diagnose the condition early enough and used his age as an excuse for his state of health.”*

## **Nursing or residential home care**

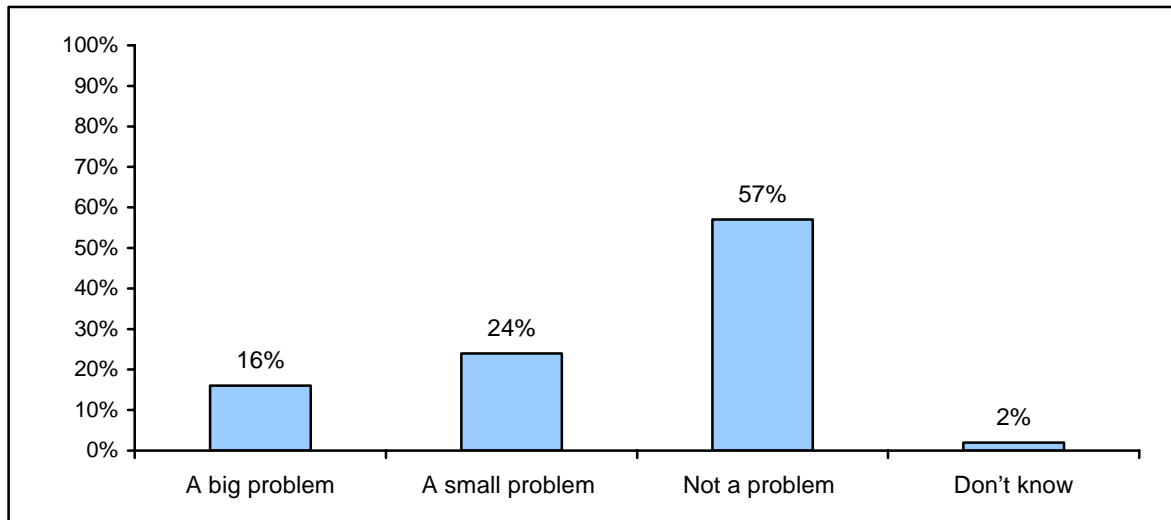
58. This section relates to any time the person that died spent in a nursing or residential home during the last three months of their life.
59. Respondents were asked whether, in the last three months of life, the person they cared for had a health problem for which they needed care in a nursing or residential home. Of those who responded to this question, 30 per cent had and 50 per cent had not. In addition:
- those aged 75+ were more likely to have had care in a nursing or residential home (37 per cent) than those aged 55-74 (11 per cent)
  - those who died of neurological conditions were more likely to have had care in a nursing or residential home (62 per cent) than those who died of cancer or organ failure (14 per cent and 34 per cent respectively)
  - A higher proportion of women (33 per cent) had this type of care than men (24 per cent).
60. Exhibit 14 shows that most carers' felt it was not a problem to access this type of care.



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## Exhibit 14

### How much of a problem, if any, was it to get nursing or residential home care?



The figures are the percentage of all who needed care in a nursing or residential home in last three months (295).

Source: Question C2

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61. Additional comments about this type of care included concerns about inexperienced staff, lack of training, high staff turnover, poor pay of nursing home staff, lack of supervision, as well as reporting very positive experiences:

*“My mother died aged 100, I don’t think she would have reached this age if the wonderful care she received at the care home had not been available”*

*“The staff were kind and tried their best in difficult circumstances”*

*“It must be remembered that elderly people are not totally stupid and deserve a lot more care and attention in residential care than is provided at present.”*

## Hospital care

62. This section relates to the last overnight stay in hospital during the last three months of life. Almost three quarters (72 per cent) of respondents reported that the person they cared for stayed in hospital for more than 24 hours at some time during the last three months of life.

- eighty-one per cent of those who died in a hospice had a hospital stay in the last three months of their life. This was significantly more than the number who died at home (36 per cent) or in a nursing or residential care home (38 per cent)
- more men (79 per cent) than women (67 per cent) had a stay in hospital in the last three months of their life
- people who died of cancer were more likely to have had a stay in hospital (78 per cent) than people who died of organ failure (69 per cent) or neurological conditions (62 per cent).

63. The hospitals that patients stayed in are listed in **Appendix 6**.

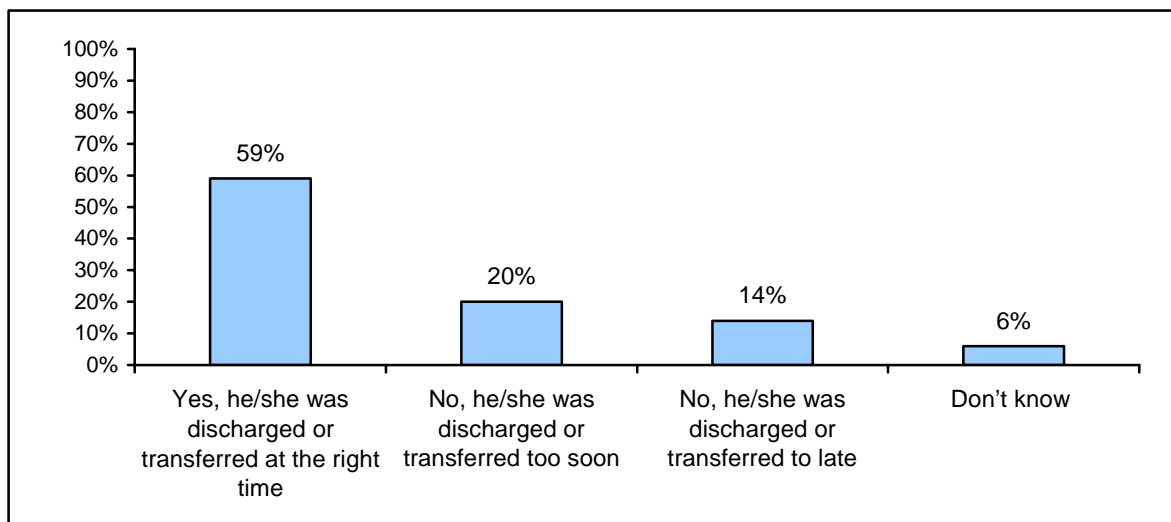
### Timing of discharge or transfer

64. Around half (53 per cent) of those who had stayed in hospital were not discharged but died during that admission. Carers of those who were discharged or transferred reported on the time of transfer or discharge (Exhibit 15).

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#### Exhibit 15

**Thinking about this last admission to hospital, do you feel that the person you cared for was discharged or transferred at the right time?**



The figures are the percentage of all patients discharged or transferred from hospital (317).

Source: Question D3

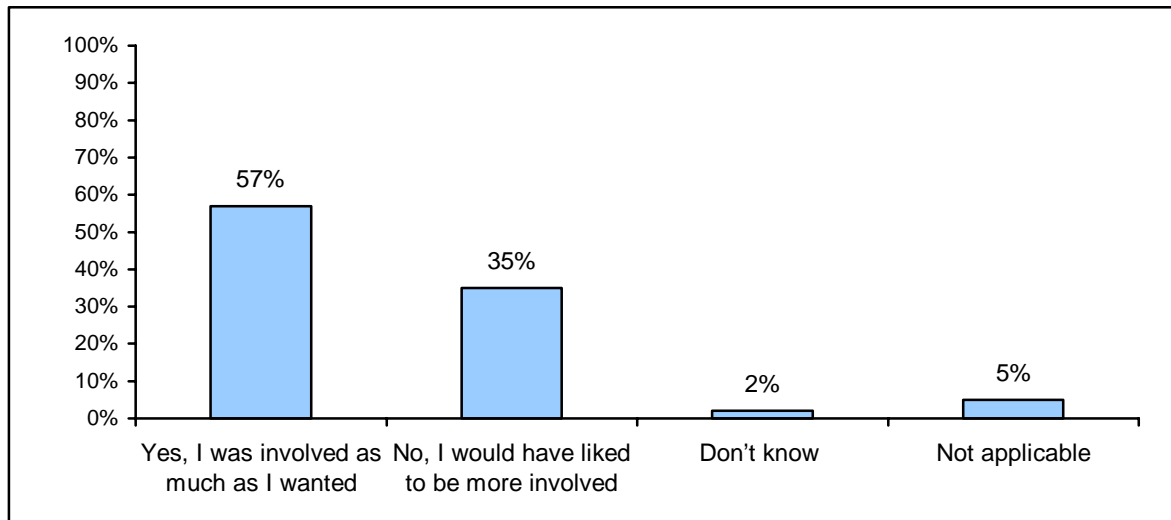
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65. Exhibit 16 shows respondents' views on their level of involvement in decisions about the treatment and care of the person they cared for when they were in hospital.

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## Exhibit 16

### Were you involved in decisions about his/her treatment and care as much as you wanted?



The figures are the percentage of all who stayed in hospital for more than 24 hours at any time during last three months of life (718).

Source: Question D4

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66. A higher proportion of those caring for people in Fife would have liked more involvement in decisions about treatment and care (41 per cent) compared with those from Highland (29 per cent).

67. Additional comments on hospital care included:

*“The nursing staff are to be commended for care, attention and sympathy given to the family”*

*“Very satisfied with and grateful for the care and attention given by doctors at hospitals. The hospital care was excellent”*

*“Staff shortages led to poor standard of care”*

*“The staff were helpful on the Palliative Care Ward but on the general ward they were less friendly, and would not explain procedures”*

*“The hospital ward was filthy – I never saw it being cleaned.”*

## Hospice care

68. Eleven percent of respondents said the person they cared for stayed in a hospice or palliative care unit, for a period of 24 hours or more, during the last three months of their life.
- People who died of cancer were more likely (28 per cent) than those who died of other conditions (2 per cent) to have stayed in a hospice or palliative care unit.
  - People in Fife (17 per cent) were more likely to have stayed in a hospice or palliative care unit than people in Borders (seven per cent) or Highland (eight per cent).
  - Only 7 per cent of patients aged over 75 years when they died 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.
69. The hospices or palliative care units that patients had stayed in, as named by respondents, are shown in Exhibit 17.

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### Exhibit 17

#### Name of hospice or palliative care unit

Victoria Hospice (NHS Fife), Kirkcaldy
Highland Hospice, Inverness
Queen Margaret Hospital, Hospice Ward 16, Dunfermline
St Margaret of Scotland Hospice, Clydebank
Prince & Princess of Wales Hospice, Greater Glasgow and Clyde
Accord Hospice, Paisley
Marie Curie Hospice, Greater Glasgow and Clyde
Macmillan Centre, Borders General Hospital <sup>10</sup>
Ardgowan Hospice, Greenock
St Vincent's Hospice, Johnstone

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### Timing of discharge or transfer

70. Half of the people who stayed in a hospice or palliative care unit (51 per cent) died there on that admission. Exhibit 18 presents the carers' views on timing of discharge or transfer for the remaining patients.

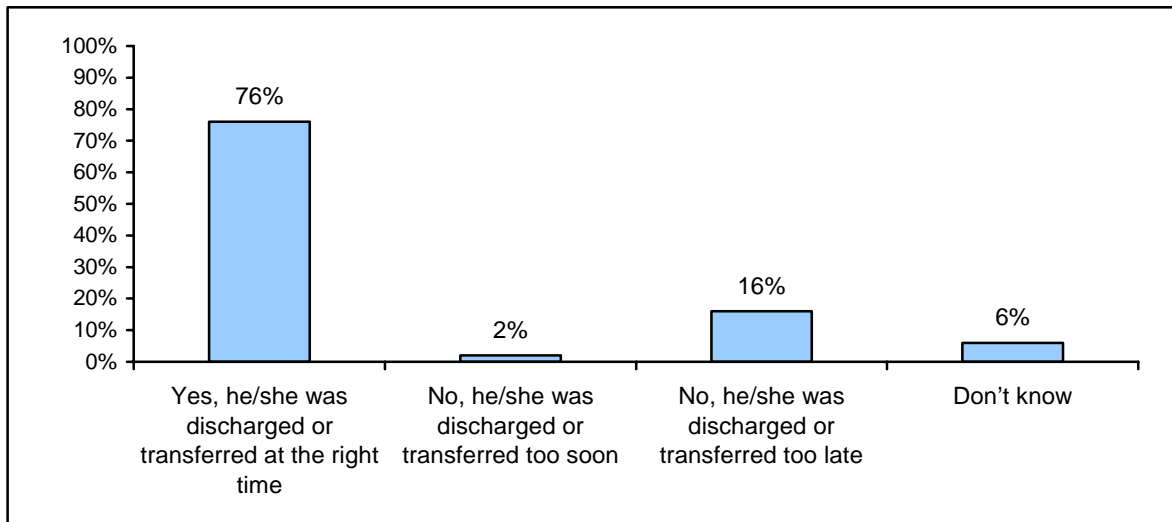
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<sup>10</sup> This is a specialist palliative care unit.

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### Exhibit 18

Thinking about this last admission to hospice, do you feel he/she was discharged or transferred at the right time?



The figures are the percentage of all discharged or transferred from a hospice (51).

Source: Question E3

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71. Additional comments about hospice care were almost all positive, for example:

*“Excellent care at the hospice”*

*“Hospice staff were supportive.”*

# Part 4. Meeting patients' and carers' needs

## Personal and physical care needs

72. One of the objectives of the study was to establish the extent to which patients' physical needs were addressed by local palliative care services. To this end, a number of questions relating to personal care needs and to the treatment of pain were included in the questionnaire.

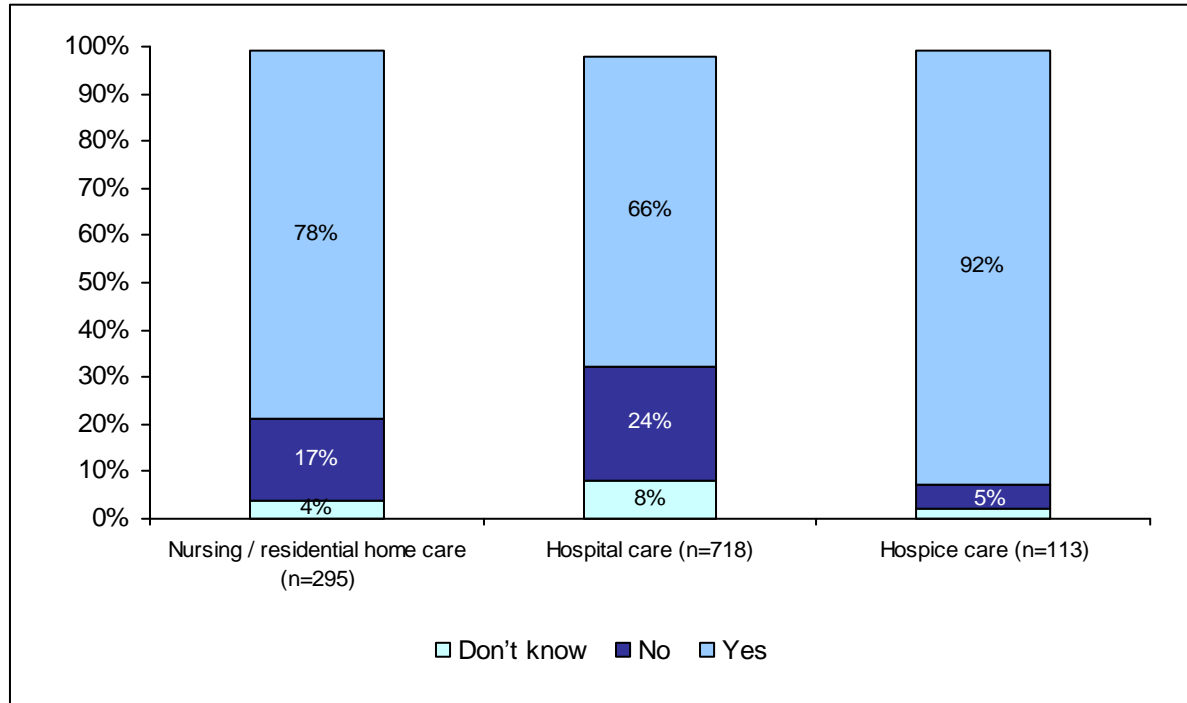
### Personal care needs

73. Where the person that died received care in a nursing or residential home, hospital and/or hospice in the last three months of life, respondents were asked whether there was enough help available to meet personal care needs, such as bathing, dressing, help with eating and going to the bathroom (Exhibit 19).

---

#### Exhibit 19

**Was there enough help available to meet personal care needs, such as bathing, dressing, help with eating, and going to the bathroom?**



The figures are the percentage of all those receiving care in the different settings during the last three months of life.

Source: Questions C4, D6 and E5

---

## Nursing or residential home care

74. Carers of those aged 75+ (80 per cent) were more likely to agree there was enough help available to meet personal care needs than carers of those aged 55-74 (52 per cent).
75. A greater proportion of carers of people who eventually died in a residential or nursing home (84 per cent) agreed that there was enough help in meeting personal care needs than carers of those who died in a hospital (63 per cent).

## Hospital care

76. Across NHS boards, people from the Highland (76 per cent) were more likely to have had their personal care needs met than those from Greater Glasgow and Clyde (63 per cent) and Fife (58 per cent).
77. Seventy-four per cent of carers of people classified as comfortably off believed there was enough help available to meet personal care needs compared with 58 per cent for both the urban prosperous and moderate means categories.

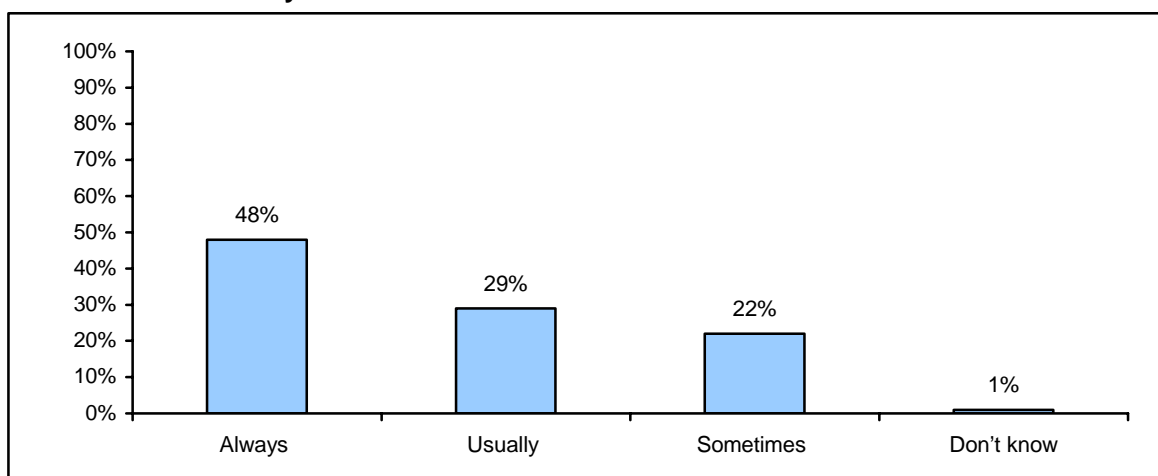
## Personal care at home

78. Where the person that died had a health problem for which they needed care at home, respondents were asked if personal care needs were taken care of by health and social services as well as they should have been (Exhibit 20).

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### Exhibit 20

**When he/she was at home during the last three months of life, were his/her personal care needs, such as bathing, dressing, and changing bedding, taken care of by health and social services as well as they should have been?**



The figures are the percentage of all who received help at home in last three months, and whose personal care needs were taken care of by health and social services (297).

Source: Question A6

---

79. 58 per cent of carers of people who died of cancer said personal care needs were always met by health and social services, compared with 40 per cent of carers of those who died of organ failure.

80. Additional comments by respondents provide some insight into perceptions of what was missing:

*“She needed more help from social services and help with personal care and pain relief but did not ask for it and did not want strangers coming into her house. I did the best I could but she died undernourished and in pain, although I know it was her choice”*

*“I wanted more ‘hands on’ help – I had to do all the bed-bathing and help with dressing myself – nurses just chatted to me and did nothing”*

*“I did not receive enough help for his personal care at home until the last 5 weeks. This was not soon enough.”*

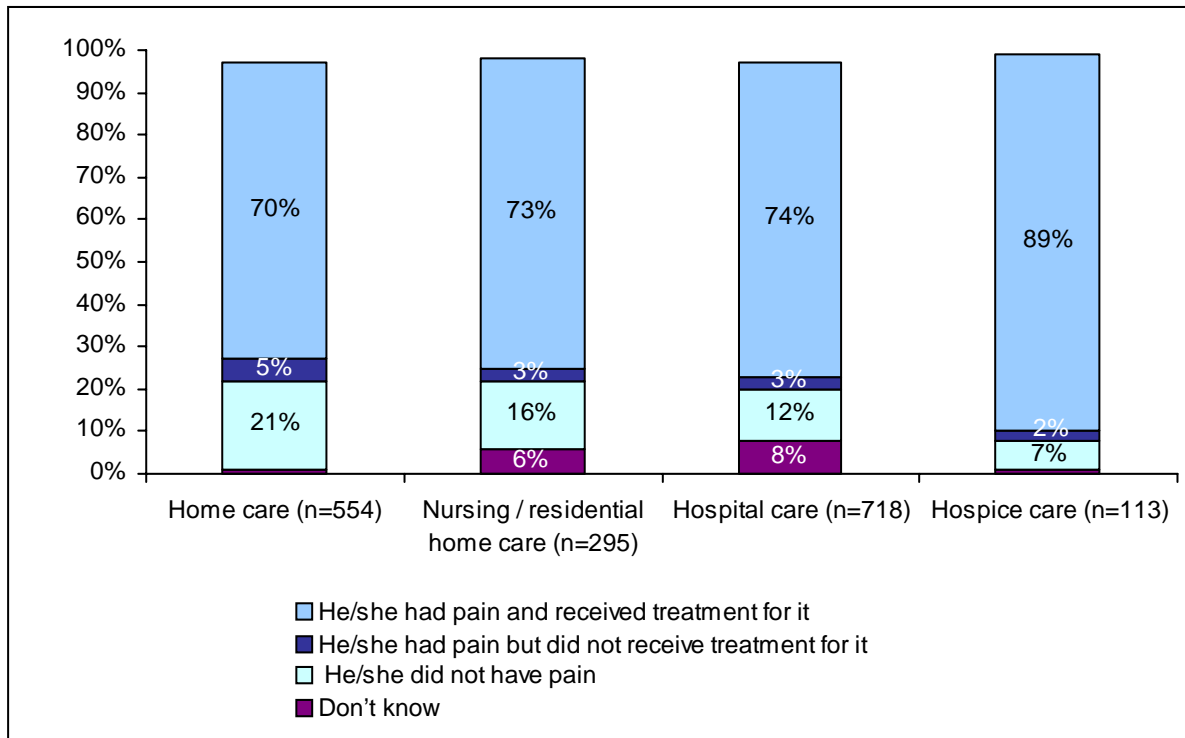


## Treatment for pain

81. Pain is more common in some illnesses and conditions than others and the findings in relation to treatment and relief of pain are therefore influenced by the cause of death. Respondents were asked whether the person that died received any treatment for pain (Exhibit 21).

### Exhibit 21

**If he/she had pain, did he/she have any treatment for his/her pain?**



The figures are the percentage of all those receiving care in the different settings during the last three months of life

Source: Questions A7, C5, D7, E6

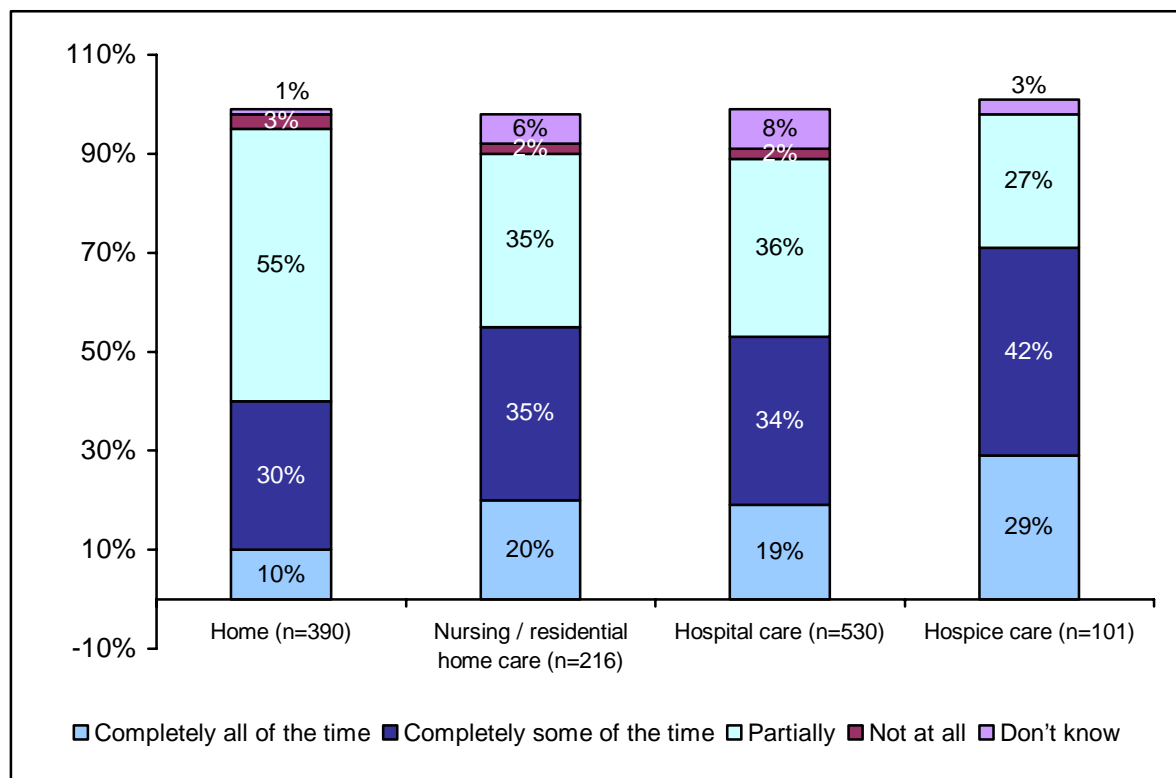
82. Across all care settings, cancer patients were more likely to have had pain and treatment for pain than those who died of other causes. The number of patients who had pain but did not receive treatment for it was low and there was no significant difference across different conditions.

## Relief of pain

83. The same respondents were asked whether the treatment relieved the pain of the person they cared for (Exhibit 22).

### Exhibit 22

**For patients receiving treatment for pain while being cared for in each setting in the last three months of life: Did the treatment relieve his/her pain?**



The figures are the percentage of all those receiving treatment for pain in the different settings during the last three months of life.

Source: Questions A8, C6, D8 and E7

84. A higher percentage of those who died at the home of a family member or friend (27 per cent) or in their own home (20 per cent) received treatment which relieved pain completely all of the time compared with those who died at a hospital (5 per cent) or hospice (5 per cent). This may reflect that those who died in hospital or hospice were admitted there because of pain which was more difficult to control.
85. For patients who spent an overnight in hospital during their last three months, those who died of neurological conditions were more likely to have received treatment which their carers believe completely relieved their pain all of the time than those who died of cancer (35 per cent and 18 per cent respectively).
86. A number of respondents made comments in relation to pain and the relief of pain:

*“The doctor did nothing to relieve his pain”*

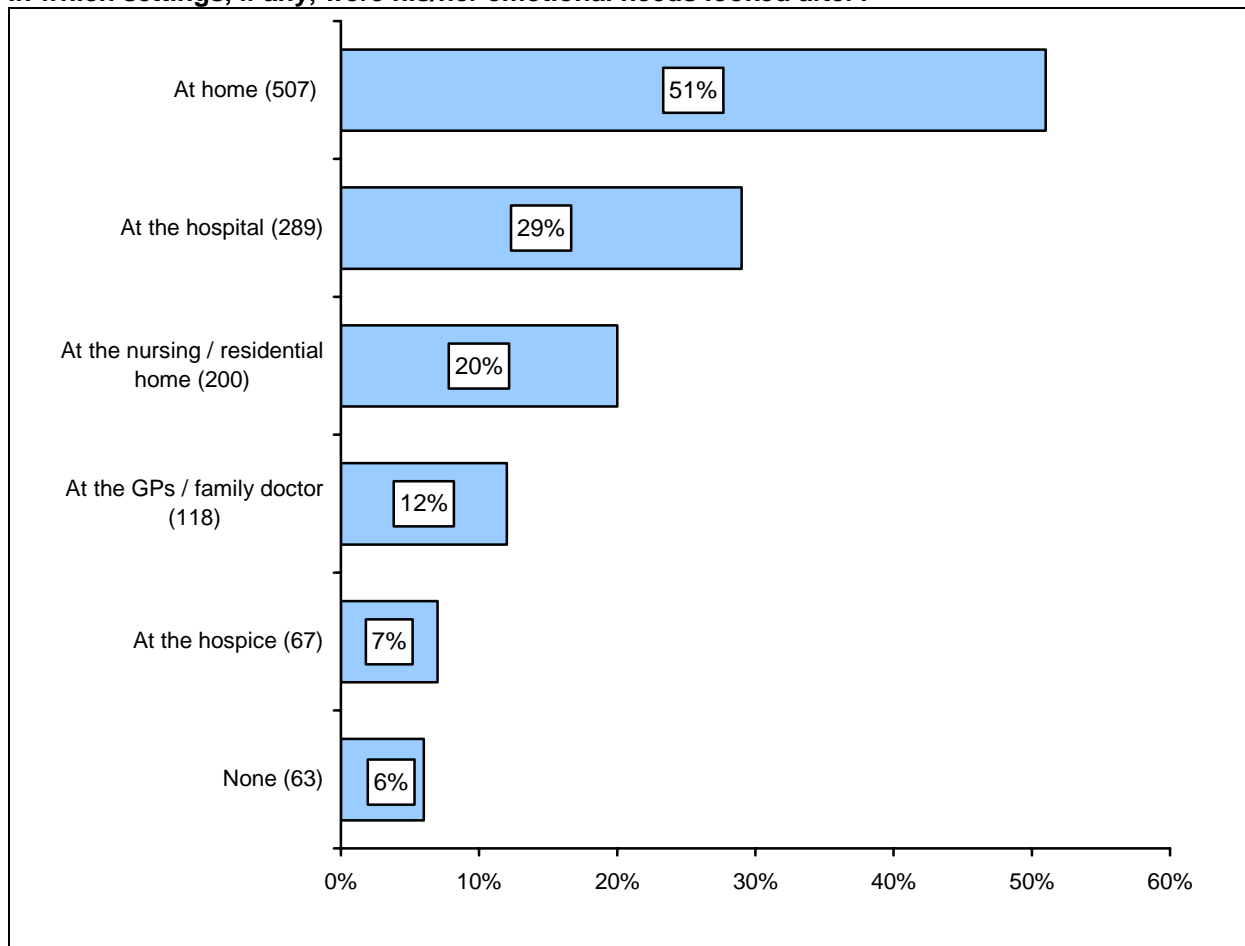
*“I expected him to be kept pain free and he wasn’t although they had agreed to do so. The nurses wouldn’t give him pain killers.”*

## Emotional needs

87. A further objective of the study was to assess whether patients’ psychosocial and emotional needs were addressed in the settings where they received care. All respondents were asked where they felt the emotional needs of the person that died were looked after, and could select more than one answer (Exhibit 23).

### Exhibit 23

**In which settings, if any, were his/her emotional needs looked after?**



The figures are the percentage of all respondents (997). Values below five per cent not presented.

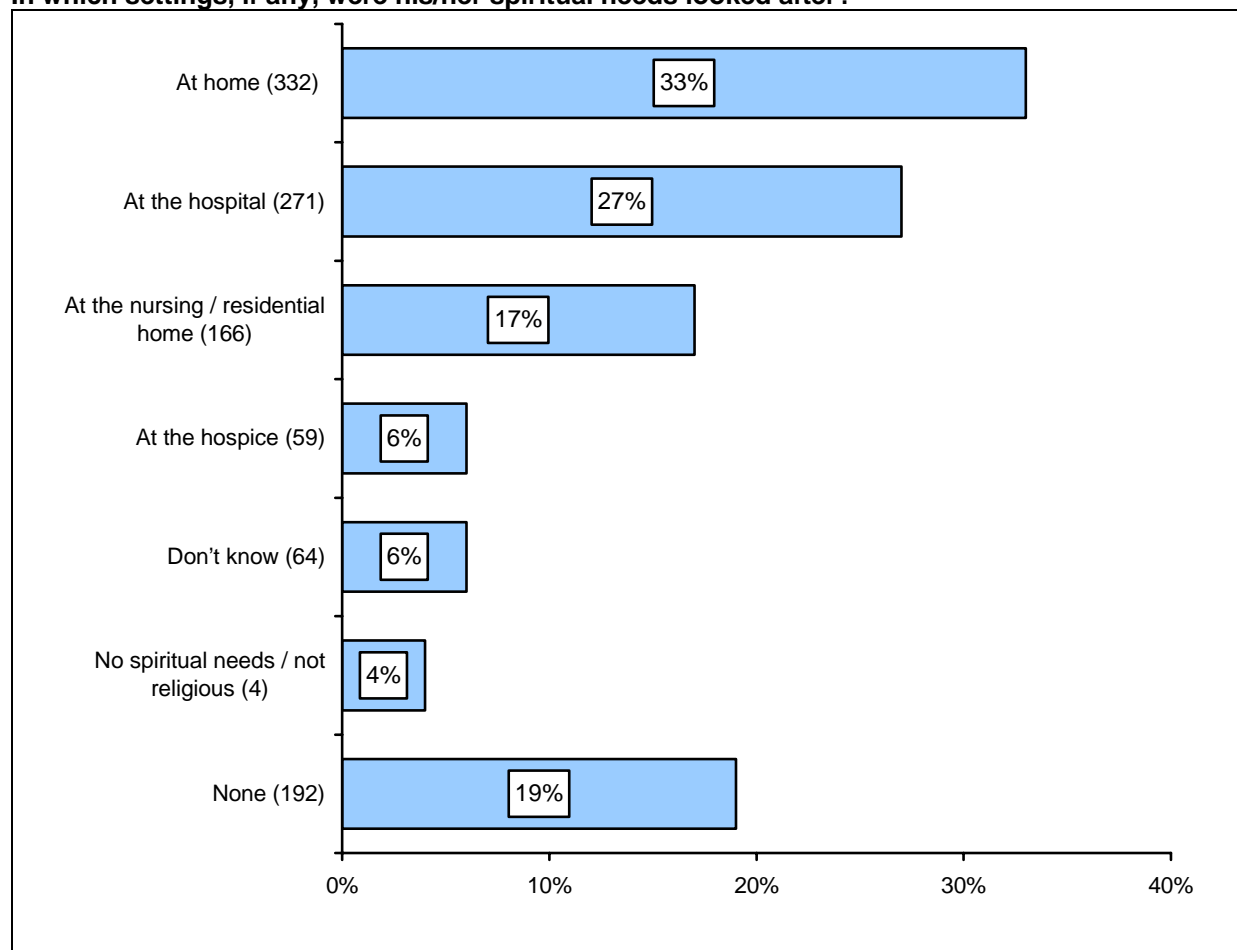
Source: Question i8

## Spiritual needs

88. To establish in which settings patients' spiritual needs were addressed, all respondents were asked to indicate the settings where the spiritual needs of the person that died were looked after (Exhibit 24).

### Exhibit 24

**In which settings, if any, were his/her spiritual needs looked after?**



The figures are the percentage of all respondents (997). Values below four per cent not presented.

Source: Question i7

## Communication

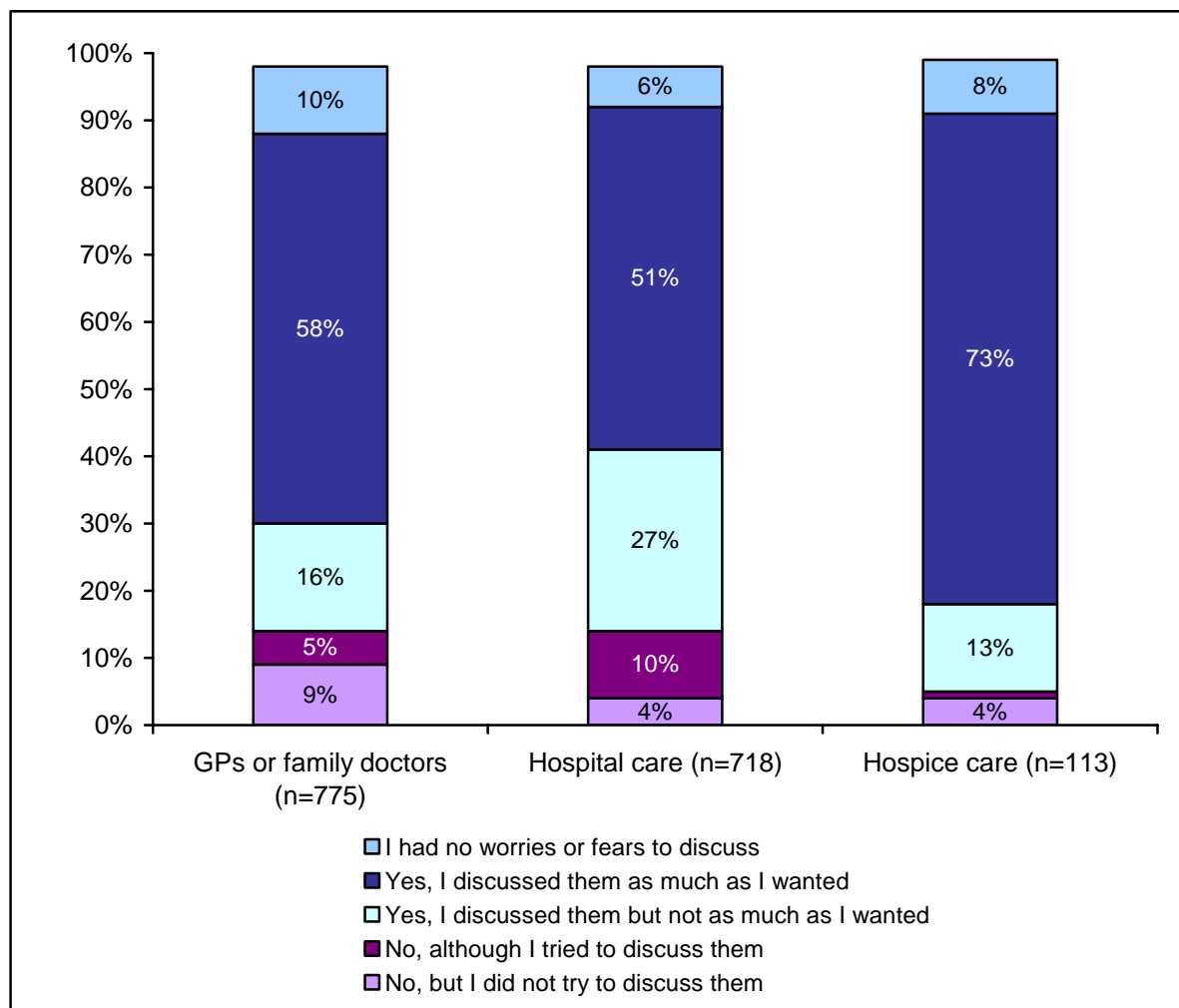
89. The survey also looked at informal carers' experiences and views in relation to information received from, and communication with, service providers.

## Discussions with health professionals

90. Various sections of the questionnaire asked respondents whether they were able to discuss with health professionals worries or fears about the condition of, treatment of, or tests for, the person they cared for (Exhibit 25).

## Exhibit 25

**Were you able to discuss with the GPs / doctors, nurses or other hospital/hospice staff any worries or fears you had about the condition, treatment or tests for the person you cared for?**



The figures are the percentage of all those who receiving home care in the different settings during the last three months of life. Values below four per cent not presented.

Source: Questions B3, D9, E8

## GPs

91. Carers of those who died of cancer reported that they were more likely to have been able to discuss their worries or fears with the GP as much as they wanted (65 per cent) than were carers of those who died of organ failure (55 per cent) or neurological conditions (39 per cent).
92. Carers of wealthy achievers were more likely than those who were comfortably off, of moderate means or hard pressed, to say they had been able to discuss worries or fears as much as they wanted (68 per cent compared with 56 per cent, 51 per cent and 52 per cent respectively).

## **Doctors, nurses and other hospital staff**

93. A greater proportion of those who cared for someone in the 18-54 age range reported that they were unable to discuss their worries or fears with hospital staff, though they tried to (29 per cent) than those who cared for someone in the 55-74 and 75+ age ranges (6 per cent and 9 per cent respectively).
94. A number of respondents commented on communication between themselves and health professionals:

*“I had to approach doctors / nurses to ask about treatment, medication etc. They were not forthcoming. It was as if it was a secret”*

*“We had to fight to get any information – departments within the hospital do not talk to each other”*

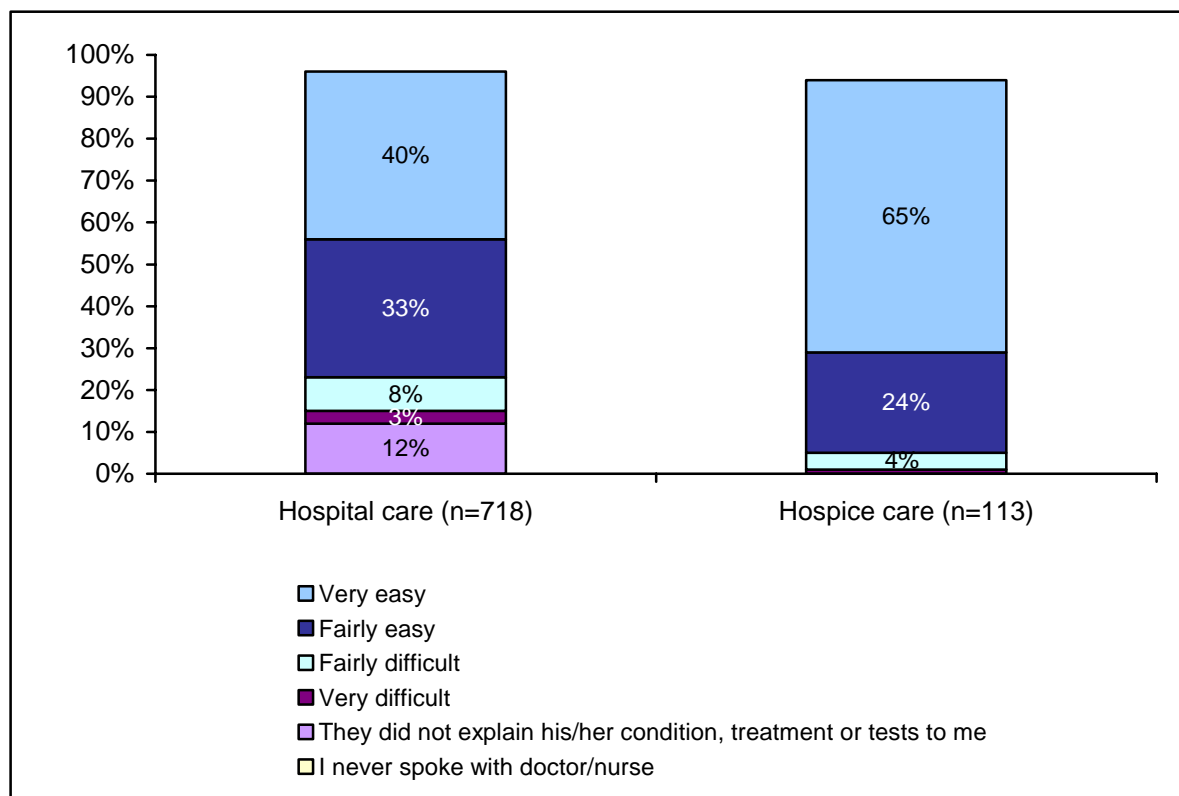
*“Difficult to find a doctor to speak to – they were always in a meeting or at lunch.”*

## **Explanations of condition, treatment or tests**

95. Exhibit 26 shows how easy respondents found it to understand the explanations provided by health professionals.

## Exhibit 26

During this hospital / hospice stay, did the doctors and nurses explain his/her condition, treatment or tests in a way that you found easy or difficult to understand?



The figures are the percentage of all those receiving hospital care (stay over 24 hours) during the last three months of life (718) and all those receiving hospice care for more than 24 hours during the last three months of life (113). Values under three per cent not presented.

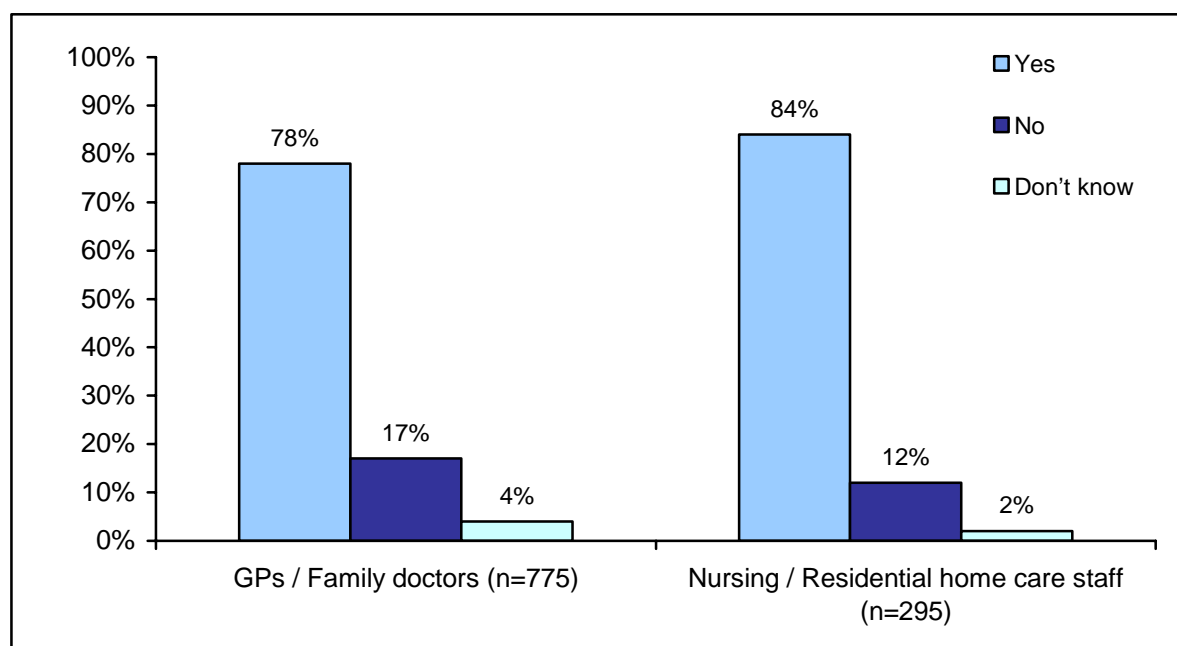
Source: Questions D5 and E4

## Time for communication

96. All respondents who provided information about someone who was cared for at home or in a nursing or residential home were asked whether or not they felt GP(s) and nursing home staff had time to listen and discuss things with them during the last three months of the person's life (Exhibit 27).

## Exhibit 27

**Do you feel that the GPs / nursing or residential home care staff had time to listen and discuss things with you?**



The figures are the percentage of all those who received home care during the last three months of life who found it very easy, fairly easy, fairly difficult or very difficult to get a doctor to visit (775) and the percentage of all those receiving nursing or residential home care during last three months of life (295).

Source: Questions B2 and C3

## GPs

97. Those who cared for someone in Highland were more likely to agree their GP had time to listen and discuss things with them (84 per cent) than those caring for someone in Greater Glasgow and Clyde (72 per cent).
98. A higher proportion of those who cared for someone who died at home (84 per cent) felt their GP had time to listen and discuss things with them than those caring for someone who died in a nursing or residential home (73 per cent) or a hospital (74 per cent).
99. A greater proportion of those who cared for wealthy achievers (85 per cent) agreed their GP had time to listen and discuss things with them than those who cared for people who were comfortably off (75 per cent), of moderate means (72 per cent) or hard pressed (76 per cent).
100. Carers of those who died of cancer were more likely to agree their GP had time to listen and discuss things with them (84 per cent) than those who cared for someone who died of organ failure (75 per cent) or neurological conditions (66 per cent).



## Nursing or residential home care staff

101. A greater proportion of those who cared for a wealthy achiever (90 per cent) or someone comfortably off (91 per cent) agreed that nursing home staff had time to listen and discuss things with them than those who cared for someone who was hard pressed (74 per cent).

102. The following quote represents a positive view point in relation to nursing or residential home care staff:

*“Throughout her illness the most help, advice, reassurance and opportunities to talk to someone came from the nursing home staff. I got nothing from the other sources.”*

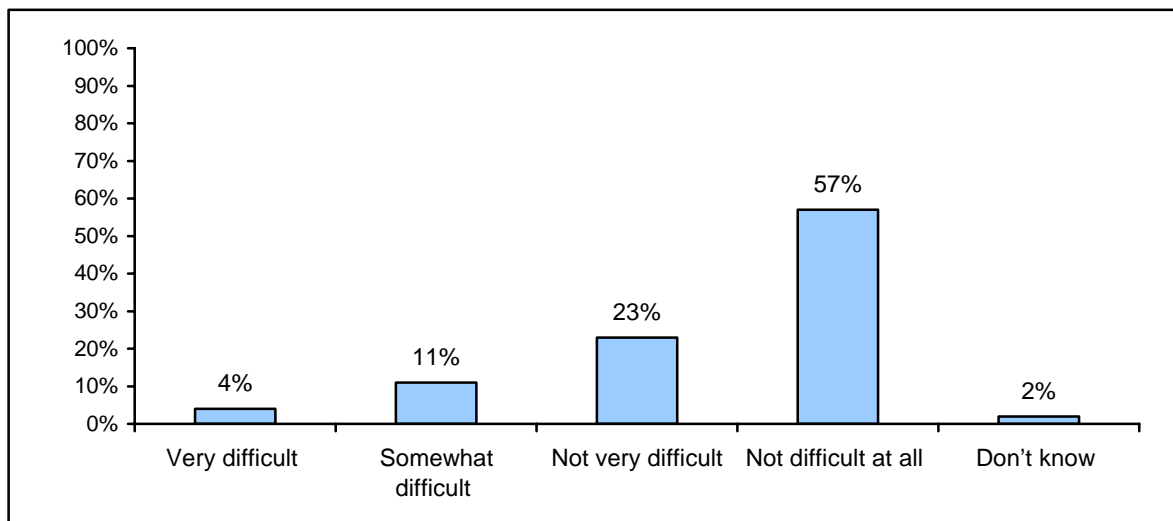
## Cost of end of life care

103. All respondents were asked about the cost of care at the end of life (Exhibit 28).

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### Exhibit 28

**How difficult was it for the person you cared for and his/her family to cover the cost of care at the end of his/her life?**



The figures are the percentage of all respondents (997).

Source: Question i6

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- For those living in Fife, 62 per cent reported that covering the cost of care was not at all difficult, compared with 51 per cent in Highland.
- There was a general trend that the level of difficulty decreases with the age of the person who died – 66 per cent of those caring for people under 55 reported that covering care costs was not very or not at all difficult compared to 72 per cent for those caring for someone aged 55-74 and 82 per cent of those caring for people over 75.

- There was some variation between the wealthiest and least prosperous categories, with 84 per cent of wealthy achievers reporting that meeting the cost of care was not very or not at all difficult, compared to 79 per cent of urban prosperous and 77 per cent of hard pressed respondents.
- The condition the person died of influenced views, 80 per cent of carers of people who died of cancer or of organ failure found that meeting the cost of care was not very or not at all difficult, compared to 74 per cent of those caring for someone who died of a neurological disorder.

# Part 5. Out-of-hours and respite care

## Out-of-hours services

104. This section of the report covers out-of-hours services (ie services in the evenings, overnight, at weekends and public holidays, when the GP surgery is closed) received by patients in the last three months of their life.

### Services used

105. All respondents were asked whether they or the person they cared for needed to contact out-of-hours services in relation to their illness. Fifty-three percent had done so. The results showed that:

- this proportion was highest amongst:
  - carers of people in the 18-54 (70 per cent) and 55-74 age groups (65 per cent)
  - people who died at home (67 per cent)
  - those who died in a hospice (65 per cent)
- it was lowest amongst those who died in a nursing or residential home (38 per cent)
- those who died of cancers were most likely to have needed out-of-hours services (63 per cent) and those who died of neurological conditions least likely (45 per cent)
- respondents caring for wealthy achievers were more likely to report using out-of-hours services (60 per cent) than those caring for the comfortably off (47 per cent).

106. Exhibit 29 shows the services contacted.

---

## Exhibit 29

### What 'out-of-hours' services did you contact?

Service	%
NHS 24	64
GP directly / GP contacted by nursing home	39
Dialled 999 for ambulance	21
Community nurse directly	19
Hospital ward	7
Hospice	2
Hospital emergency phone number	1
Border Care alarms	1
Other out-of-hours nursing service	1

The figures are the percentage of all who needed to contact out-of-hours services during last three months of life (532). A number of patients/carers contacted more than one service during the last three months.

Source: Question F2

---

- Carers of people in Fife were more likely to have contacted NHS 24 (72 per cent) than those caring for people in Greater Glasgow and Clyde (58 per cent).
- NHS 24 was most likely to have been used by carers of those who died at home (73 per cent) and least likely for those who died in a nursing or residential home (53 per cent).
- GPs were most likely to have been contacted for those who died in a nursing or residential home (58 per cent).
- Dialling 999 for an ambulance was most likely to have happened for those who died in hospital (29 per cent) and less so for those who died at home (15 per cent) or in a nursing or residential home (8 per cent).
- Respondents caring for people in the wealthy achievers and urban prosperous groups were more likely to have contacted a GP (42 per cent and 47 per cent) or community nurse (22 per cent and 28 per cent) directly than those in the other categories.

107. Exhibit 30 shows the results of contacts with out-of-hours services.

---

### Exhibit 30

#### What happened as a result of this contact?

	%
A GP visited the house / nursing or residential home	65
She / he was admitted to hospital or hospice	46
Advice was given on the telephone	26
A nurse visited the house	24
She / he was sent to hospital but not kept in	5
Paramedics came to the house	1
Patient not admitted to hospital / decided patient was to be cared for at home	1

The figures are the percentage of all who needed to contact out-of-hours services during last three months of life (532).

Source: Question F3

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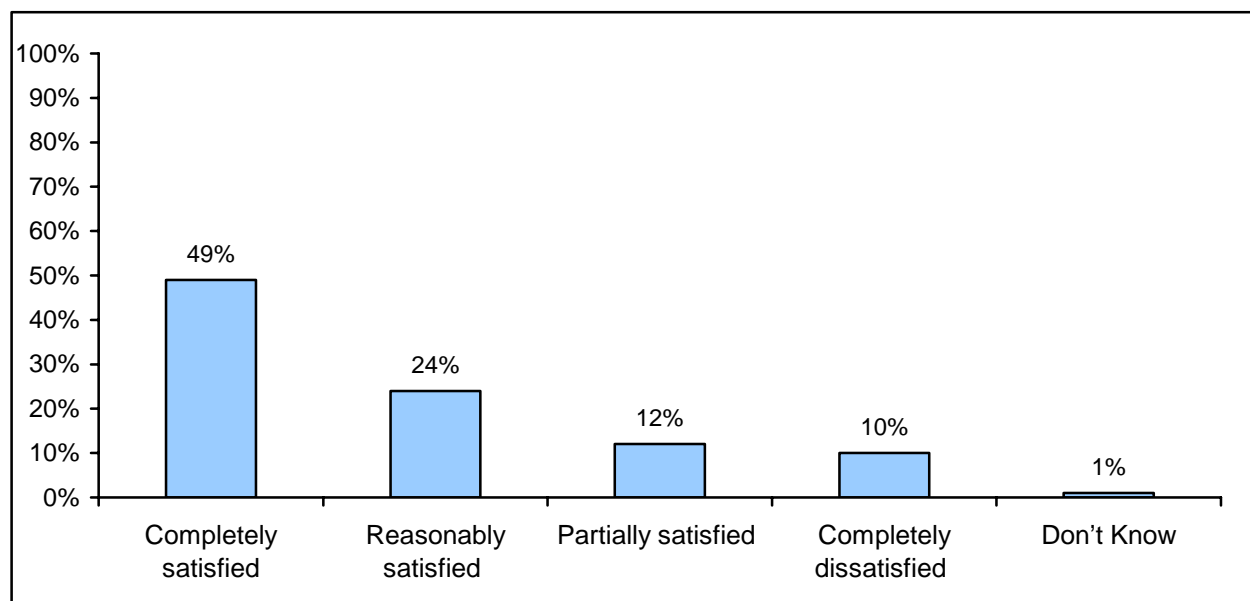
### Satisfaction with out-of-hours services

108. As Exhibit 31 shows, three quarters of respondents reported that they and the person they cared for were completely or reasonably satisfied with the response received from out-of-hours services.

---

### Exhibit 31

#### How satisfied were you and the person you cared for with the response from out-of-hours services?



The figures are the percentage of all who needed to contact out-of-hours services during last three months of life (532).

Source: Question F4

---

109. Satisfaction with out-of-hours services varied with the age of the person who died:

- 76 per cent of carers of people who died aged 75+ were at least reasonably satisfied
- 71 per cent of carers of people who died aged 55-74 were at least reasonably satisfied
- 58 per cent of carers of people who died aged under 55 were at least reasonably satisfied.

110. Some additional comments on out-of-hours services included:

*“Emergency services, ambulance crew and telephone operator were all excellent”*

*“NHS 24 were very good”*

*“The A & E staff were excellent”*

*“The arrival of the police, ambulance, and doctor when my mother died was not necessary and a waste of resources.”*

## **Respite care**

111. For the purpose of this survey, respite care is defined as ‘care that the person received during the last three months which was mainly to give the carer and/or family a rest or break’.

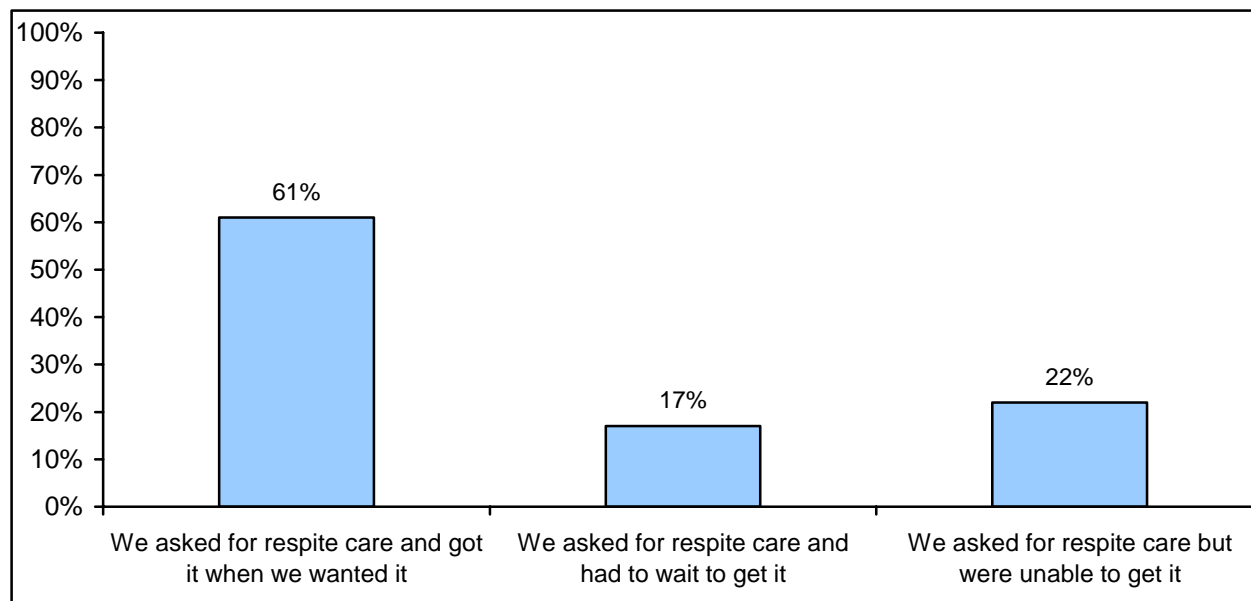
## **Access to respite care**

112. Fifty-five per cent of respondents did not ask for respite care because they did not require this service and a further seven per cent did not ask for respite care because they did not know it was available. Exhibit 32 shows responses from those who asked for respite care in relation to how easy it was to access.

---

## Exhibit 32

Did any of the following apply during the last three months?



The figures are the percentage of all respondents who asked for respite care in the last three months of life (104).

Source: Question G1

---

113. The percentage that asked for respite care and received it when they wanted was higher in Borders (64 per cent) than in Greater Glasgow and Clyde (20 per cent).

114. Seventy-seven per cent of respondents who used respite care reported that they got as much respite care as they needed.

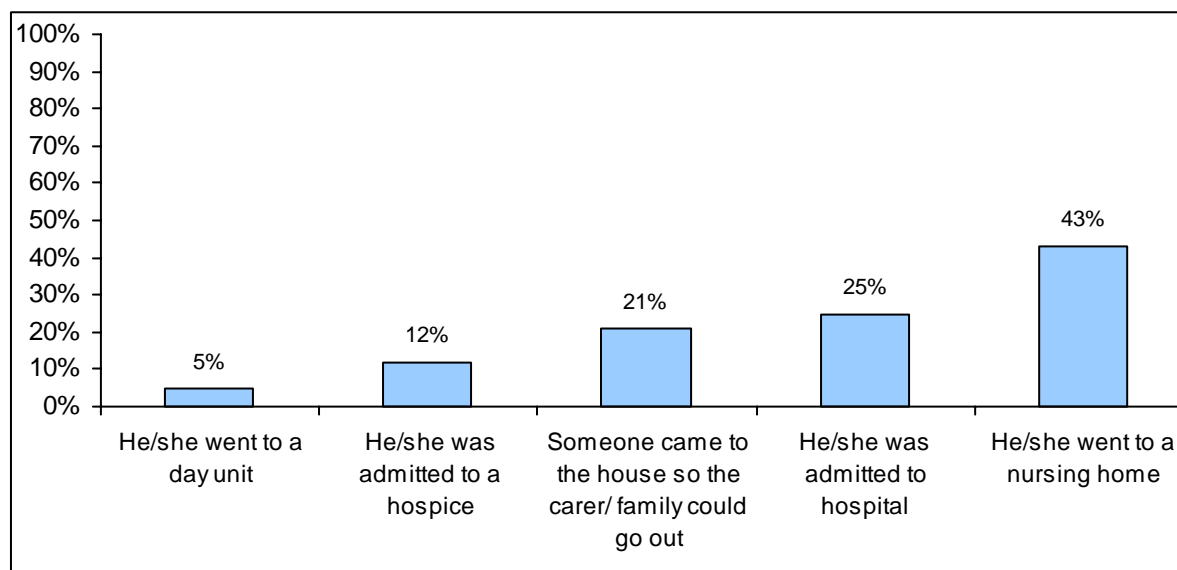
## Location of respite care

115. Those who received respite care services during the last three months were asked where the respite care took place (Exhibit 33).

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### Exhibit 33

#### Where did he/she go for respite care during the last three months?



The figures are the percentage of all who received respite care during last three months of life (81).

Source: Question G2

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116. Small numbers responding to this question mean that it is difficult to report variations with confidence, but broadly speaking:

- hospital was most likely to be the respite setting for those who died of cancer (39 per cent) and those in Borders (60 per cent)
- in-home care was most likely to have been used for people aged under 55 (60 per cent)
- nursing homes were most used for people aged 75+ (52 per cent) and those who died of organ failure (66 per cent).



# Part 6. Care at the end of life

117. This section is concerned with the last three days of life and the care the person that died received during this time. If the care was in more than one place, the respondent was asked to answer the questions about the place he or she spent the most time in the last three days of his/her life.

## Location during the last three days of life

118. Forty-six percent of the people that died spent most of the last three days in hospital, 24 per cent at home, 21 per cent in a nursing or residential home and 7 per cent in a hospice.

- In Borders and Highland, the proportions spending most of this time in a hospice were smaller (2 per cent and 4 per cent respectively) than in Greater Glasgow and Clyde (10 per cent) and in Fife (11 per cent).
- Women were more likely to have spent this time in a nursing or residential home (26 per cent) than men (15 per cent) – this was related to age and cause of death.
- Older people were most likely to spend this time in a nursing or residential home (28 per cent of those aged 75+) and younger people at home (32 per cent of those aged under 55) – again this was related to cause of death.
- Those who died of cancer were more likely than others to have spent this time in a hospital (40 per cent) or hospice (19 per cent).
- Those who died of neurological conditions were most likely to have spent this time in a nursing or residential home (44 per cent).
- Those who died of organ failure were most likely to have spent this time in a hospital (50 per cent).

*“The Marie Curie nurses were supportive in the last few days”*

*“The residential home staff would have liked to keep her with them for her last few days but she was too ill.”*

## Carers' involvement

119. All respondents were asked whether they were involved as much as they wanted to be in decisions about treatment and care for the person that died. Sixty-nine percent said they were, 19 per cent would have liked to be more involved (22 per cent of those caring for a man and 17 per cent of those caring for a woman). Those caring for someone who died in hospital were most

likely to say they would have liked to be more involved in these decisions (26 per cent) and those caring for someone at home much less likely to say this (9 per cent).

## **Help with personal and nursing care**

120. Respondents' views were sought on the amount of help with personal and nursing care available during the last three days of life:

- eighty per cent of respondents said there was enough help available to meet personal needs (such as bathing, dressing, help with eating and going to the bathroom)
- eleven per cent said there was not enough help
- for people who spent this time in hospital, 77 per cent of their carers said there was enough such help, compared with 87 per cent for those who were in a hospice and 86 per cent for those in a nursing or residential home.

121. During the last three days, 77 per cent of carers said there was enough help with nursing care, such as getting dressings changed and with medication, and eight per cent said there was not enough. Further analysis showed that:

- for those that spent this time at home, 72 per cent of carers said there was enough such help, compared with 75 per cent for those who were in hospital, 88 per cent for those in a hospice and 84 per cent for those in a nursing or residential home
- eighty-five percent of carers of people who died of cancer, 70 per cent of carers of people who died of organ failure and 80 per cent of carers of people who died of neurological conditions said there was enough of this kind of help.

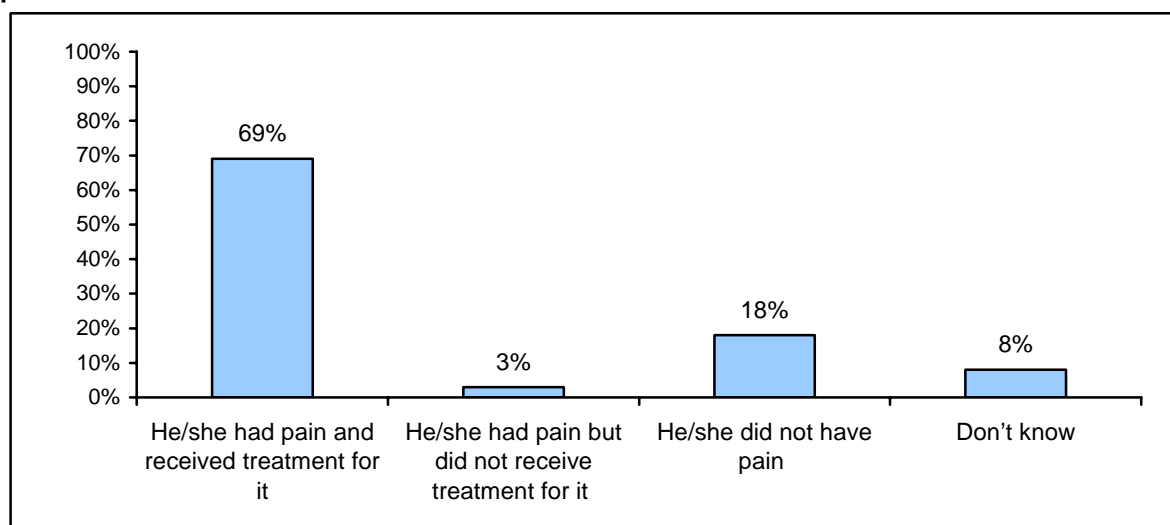
## **Treatment of pain**

122. Exhibit 34 gives information on treatment of pain in the last three days.

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### Exhibit 34

During these last three days, if he/she had pain, did he/she have any treatment for his/her pain?



The figures are the percentage of all respondents (997).

Source: Question H5

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123. A greater percentage of carers of people aged under 55 (11 per cent) than other age groups reported that the person they cared for had pain but did not receive treatment.

### Relief of pain

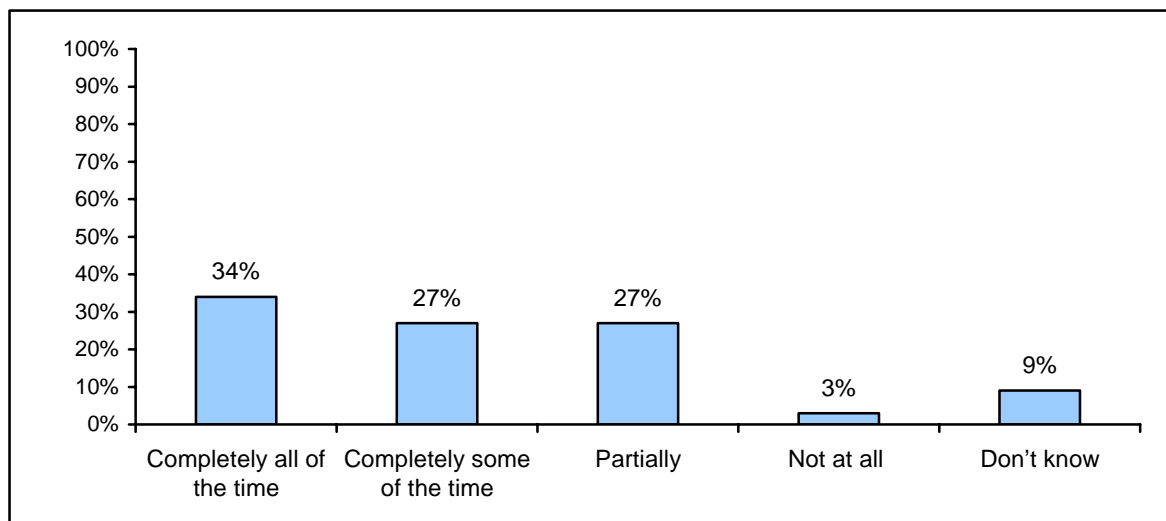
124. The degree to which carers believed that pain treatment relieved pain varied with the condition the person died of and with location during the last three days (Exhibit 35):

- the proportions reporting that pain was completely relieved all of the time were 42 per cent for people who died of neurological conditions, 41 per cent for people who died of cancer and 26 per cent for people who died of organ failure
- the proportions reporting that pain was completely relieved all of the time were 42 per cent for people in a hospice, 35 per cent for people who were at home, 34 per cent for people in a nursing or residential home and 31 per cent for people in hospital.

---

### Exhibit 35

#### Did the treatment relieve his/her pain?



The figures are the percent of all respondents who had treatment for pain (683).

Source: Question H6

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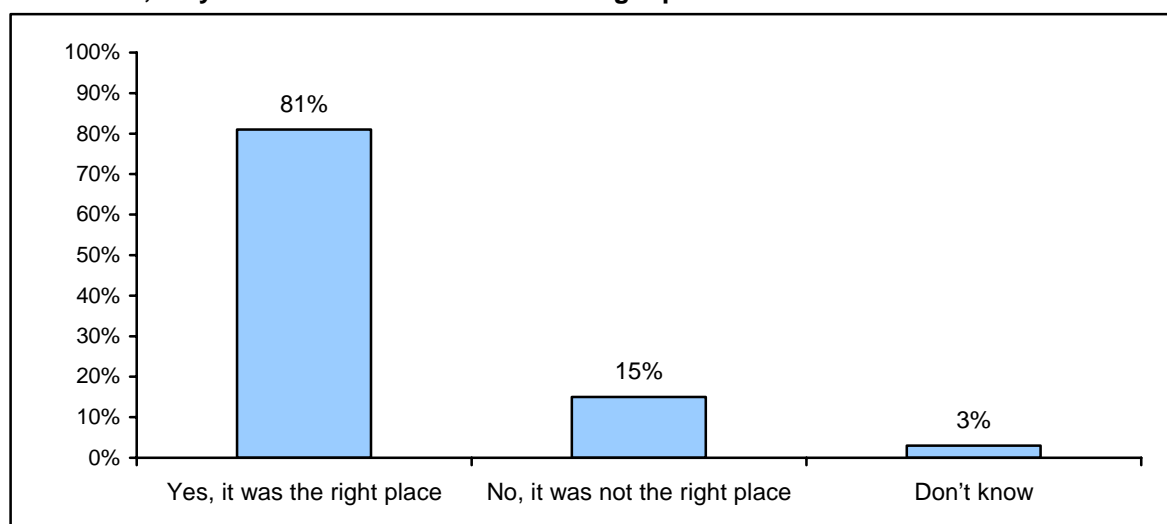
### Place of death

125. All respondents were asked whether they felt that the person they cared for died in the right place (Exhibit 36).

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### Exhibit 36

#### On balance, do you feel that he/she died in the right place?



The figures are the percentage of all respondents (997).

Source: Question i2

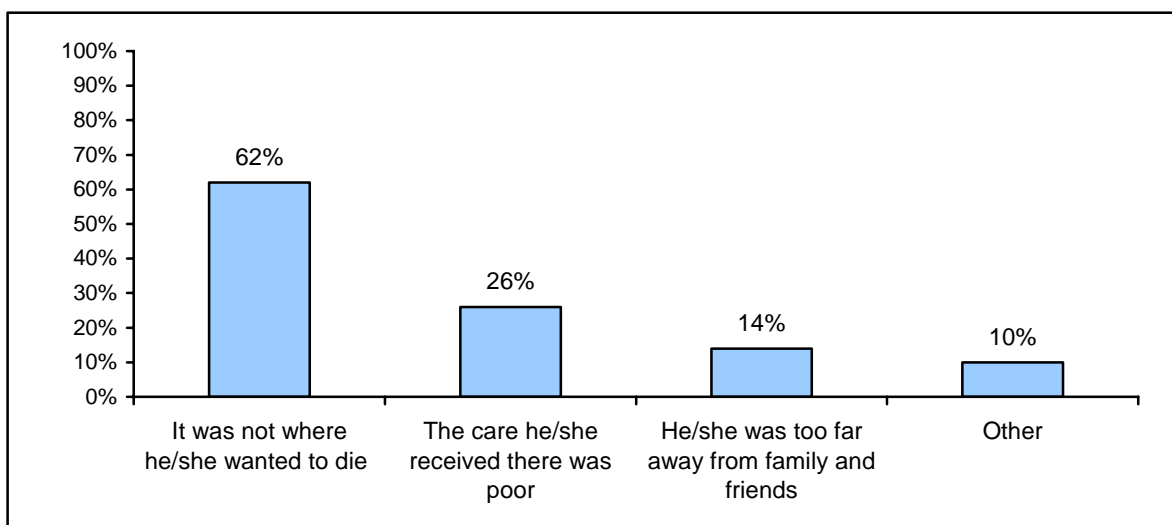
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- The percentage of respondents who felt that the person they cared for had died in the right place was higher for those where the death happened at home (96 per cent) than for those who died in a care home (82 per cent), hospice (81 per cent), or hospital (75 per cent)
- The percentage of respondents who felt that the person they cared for died in the right place was higher amongst those in Borders (91 per cent) than in Fife (78 per cent) or Greater Glasgow and Clyde (76 per cent)

126. Those respondents who thought the person they cared for did not die in the right place were asked why they felt this (Exhibit 37).

### Exhibit 37

If 'No' was it because ...



The figures are the percentage of all who felt the location was not the right place to die (154).

Source: Question i3

## Support at the end of life

127. All respondents were given the opportunity to say whether health services could have helped to make the end of life easier for the person who died. A quarter said health services could have made this time easier and two-thirds said they could not.

128. Carers of younger people were most likely to think that the health services could have made this time easier: 43 per cent of those caring for 18-54 year olds said this compared with 31 per cent of those caring for 55-74 year olds and 22 per cent of those caring for people over 75.

129. Those caring for people who died in hospital were most likely to say that the health services could have made this time easier (29 per cent) and those caring for people who died in a nursing or residential home least likely to say this (18 per cent).

130. Respondents were given the opportunity to comment further on their answer and almost a third (32 per cent) did so, providing a wide variety of comments. The largest number (8 per cent) gave positive comments about the care received. Three percent (25 people) mentioned poor communication from hospital staff or GPs.

*“He was very well cared for in all matters”*

*“Care that nursing staff provided meant that he died with great dignity  
and in peace”*

*“They did everything to make his passing as pain free as possible.”*

131. The same question was asked in relation to social services. Fifteen per cent said that social services could have made the end of life easier and 71 per cent said they could not. Respondents in Borders were less likely to say that social services could have made this time easier (6 per cent) than those in Highland (16 per cent).

132. Again, respondents were given the opportunity to comment further and 14 per cent did so, providing a variety of comments. The highest proportion (4 per cent) made negative comments about services or suggested the need for improvement in the services received. Two of the main problems reported were lack of continuity of care 24 hours a day (24 people said this) and difficulties in accessing equipment to enable patients to be cared for at home (21 people said this).

*“I’ve not got a lot of faith in them”*

*“Services should have been put in place long before she died”*

*“Staff were incompetent, insensitive, ill-informed, uninterested,  
extremely patronising and on occasion obstructive.”*

# Appendix 1. Opt-in letter



**General Register Office  
for  
SCOTLAND**  
*information about Scotland's  
people*

**Vital Events Branch**  
Ladywell House  
Ladywell Road  
Edinburgh  
EH12 7TF

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«INFSIG»	Your reference	
«INURES1»	Our reference	«GROS_REF_NO»
«INURES2»		
«INURES3»	Date	6 February 2008
«INURES4»		
«RINRESPC»		

---

Dear «Title» «SNAME»

## **Survey of informal and family carers**

We are writing to people who have registered a death in the last year to ask if they would agree to take part in a national survey about the care of people at the end of life. This important survey will form part of a wider review of end of life care currently being carried out by Audit Scotland.

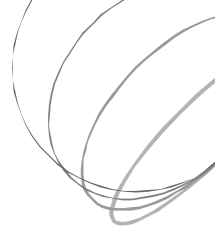
### ***Why we are writing to you***

Our records show that you registered a death in 2007 and we would therefore like to invite you to take part in the survey. The survey will involve a postal questionnaire about the care and support received by this person at the end of their life and should be completed by their main carer (this is the family member or friend who was most involved in arranging the care needed, even if that care was in a home, hospice or hospital). If this was not you, we would be grateful if you would pass this letter on to the most appropriate person.

We believe this is an important survey, since it will allow the views of people who have cared for someone who is ill to be taken into account in assessing the quality of services currently provided.

### ***What to do next***

If you are willing to take part in this survey, please return the attached permission slip in the reply paid envelope provided. The questionnaire will then be sent to you in the next two weeks. If you do not want to take part then you do not need to return the slip. If we don't hear from you, we will not contact you again.



If this letter has been passed on to you because you were the main carer, and you are willing to complete the questionnaire then please use the permission slip attached to let us know your name and address.

***How the information you provide will be used***

Audit Scotland is responsible for reviewing a range of public services, including National Health Services, to ensure that public money is wisely and properly spent. The results from the survey will be used by Audit Scotland in their national report but this will not identify any individual responses. If you decide to receive and complete the questionnaire, you will be contributing to work that will influence how services are provided to support ill people and their carers.

***What to do if you want more information***

If you have any questions about this survey, then please call Janet Biggar or Lisa Emslie on 0131 478 7536 or email [janet@george-street-research.co.uk](mailto:janet@george-street-research.co.uk).

If you would like to receive this letter or the questionnaire in a different format or language, then please let us know on the attached reply slip or contact George Street Research on the number or email address given above.

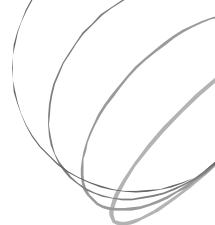
We understand that receiving this letter may be upsetting and, if so, we apologise for this. If you would like to talk to someone about how you feel, you can call Cruse Bereavement Care Scotland on 01738 444 807.

Thank you for taking the time to read this letter. I hope you will agree to take part in the survey.

Yours sincerely

Graham Jackson





# Appendix 2. Covering letter sent with questionnaire

«Title» «SNAME»  
«INURES1»  
«INURES2»  
«INURES3»  
«INURES4»  
«RINRESPC»

21 February 2008

Ref «GROS\_REF\_NO»

Dear «Title» «SNAME»

## **Informal and Family Carers Survey**

We wrote to you recently asking if you would take part in this study and we appreciate your willingness to tell us about your views and experiences of caring for someone who was ill. This survey forms part of a wider review currently being carried out by Audit Scotland. Your views on the support that is available to seriously ill people and their family/carers, are an important part of this review.

### **What to do now**

Please complete and return the questionnaire in the envelope provided, by **29th February, 2008**. If you would like to receive the questionnaire in a different format or language then please let us know.

However, if you decide not to take part then please let us know by returning the blank questionnaire in the freepost envelope. Alternatively, please call us on 0131 478 7536 or email [lisa@george-street-research.co.uk](mailto:lisa@george-street-research.co.uk). If you tell us you don't want to take part in this research then we will not contact you again.

If receiving this letter and questionnaire has caused you distress, we apologise for this. If you would like to talk to someone about how you feel, you can call Cruse Bereavement Care Scotland on 01738 444 807.

### **How the information you provide will be used**

Audit Scotland is responsible for reviewing a range of public services, including National Health Services, to ensure that public money is wisely and properly spent. The results from the survey will inform a national review of services available to people at the end of life, but this will not identify any individual responses.

The survey is being carried out by George Street Research, which is an independent research company operating in accordance with the strict code of conduct of the Market Research Society. We will not pass on any personal information about you to anyone else.

Thank-you for taking the time to read this letter. By completing the questionnaire, you will be contributing to work that will influence how services are provided to support ill people and their carers. We appreciate your help and thank you for your time.

Yours sincerely



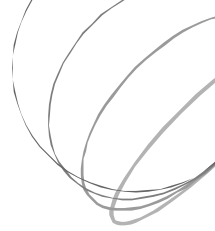
**Janet Biggar**  
Associate Director



**GEORGE STREET**  
RESEARCH

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VAT No: 502 484862

Registered Office:  
St Paul's House  
Warwick Lane  
London EC4P 4BN (UK)  
No: 2364135



# Appendix 3. Questionnaire

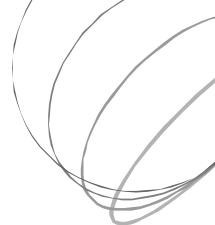
## Informal and Family Carers Questionnaire

This questionnaire is part of a national survey about the care of people at the end of life.

In order to keep the responses confidential, we have not identified the person whom you cared for but refer to the person as he throughout the questionnaire.

- Not all sections of this questionnaire will be relevant to you and we have included instructions throughout to guide you through. Please start at the beginning and then follow the instructions as you come to them
- The questions are arranged in sections, each covering a different setting or type of service:
  - Section A: Care at Home
  - Section B: GPs or Family Doctors
  - Section C: Nursing/ Residential Home Care
  - Section D: Hospital Care
  - Section E: Hospice Care
  - Section F: Out-of-hours Services
  - Section G: Respite Care
  - Section H: Last three days of Life
  - Section I: Other Care Issues
- As you go through the questionnaire, please follow the instructions and answer the questions by circling the most appropriate statement
- If you would rather not answer one of the questions, please go on to the next one.
- We are very interested in what you have to say. Please continue on extra sheets if necessary

If you have any questions about this survey, then please call Janet Biggar or Lisa Emslie on 0131 478 7536 or email [lisa@george-street-research.co.uk](mailto:lisa@george-street-research.co.uk).



## Section A: Care at Home

The following questions are about the support the person you cared for received at **home** during the **last three months** of life. If the person you cared for was not at home during this time, please follow the instruction at question **A1**.

**A1** In the last three months, did the person you cared for have a health problem for which he needed home care, such as assistance with home nursing, help with bathing or dressing, or help with basic household tasks? (Please circle one option)

Yes	1	<b>Go to A2</b>
No	2	<b>Go to Section B</b>
Not applicable, he was not at home in the last three months	3	<b>Go to Section B</b>

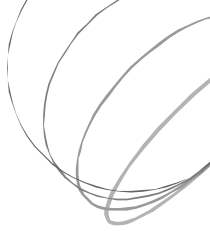
**A2** In the last three months of life, did the person you cared for receive any help at home from any of the services listed below? (Please circle all options that apply)

A district or community nurse	1
A Macmillan nurse or hospice nurse	2
A Marie Curie nurse	3
Any other nurse at home	4
A home care worker, home care aide, or home help	5
Don't know	6
None	7
Other (please write in)	8

-----

**A3** How much of a problem, if any, was it to get help at home from any of the services listed above? (Please circle one option)

A big problem	1
A small problem	2
Not a problem	3
Don't know	4



**A4** Patients are entitled to an assessment of their needs in order to receive services and support – this is called a Community Care Assessment and may be undertaken by an occupational therapist or local social work department.

Was the person you were caring for offered a Community Care Assessment? (Please circle one option)

Yes	1
No	2
Don't know	3

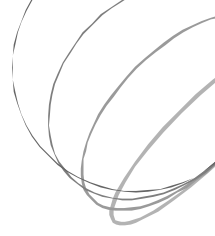
**A5** Please can you tell us what services, if any, he received? (Please circle all options that apply)

Help with meals (eg meals on wheels)	1
Help with housework	2
Help with shopping	3
Sitter services	4
Day care services	5
Respite care	6
Short breaks	7
Community alarms	8
Help with personal care such as bathing and dressing	9
Equipment (eg pressure relieving mattresses, bedpans or walking frames)	10
Adaptations (eg raising your bed, chair or toilet seat, putting in grab rails or ramps)	11
Transport	12
Residential accommodation	13
None	14
Other (please write in)	15

-----

**A6** When he was at home during the last three months of life, were his personal care needs, such as bathing, dressing, and changing bedding, taken care of by health and social services as well as they should have been? (Please circle one option)

Always	1
Usually	2
Sometimes	3
Don't know	4
Not applicable, personal care needs were not taken care of by health and social services	5



**A7** During the last three months of life, while the person you cared for was at home (not in a residential or nursing home), if he had pain, did he have any treatment for his pain? (Please circle one option):

He had pain and received treatment for it	1	<b>Go to A8</b>
He had pain but did not receive treatment for it	2	<b>Go to A9</b>
He did not have pain	3	<b>Go to A9</b>
Don't know	4	<b>Go to A9</b>

**A8** Did the treatment relieve his pain (Please circle one option):

Completely all of the time	1
Completely some of the time	2
Partially	3
Not at all	4
Don't know	5

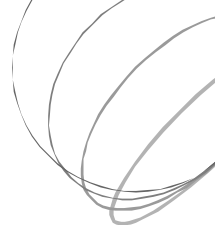
**A9** During the time you were caring for him, were you offered a Carer's Assessment to identify any needs you might have to help you in your role as carer? (Please circle one option)

Yes	1
No	2
Don't know	3

**A10** Please can you tell us what support you received to help you in caring for him? (Please circle all options that apply)

Received help with cleaning	1
Received help with washing	2
Received money for taxi fares	3
Received a mobile phone	4
Received information on benefits I might be entitled to claim	5
Received information on support such as from carers groups	6
Received support to give me a break (eg a sitting service)	7
None	8
Other (please write in)	9

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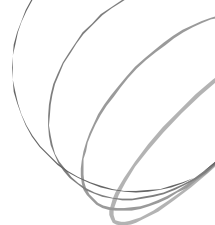


**A11** Overall, do you feel that you and your family got as much help and support from **health services**, such as nurses, as you wanted when caring for him? (Please circle one option)

Yes, we got as much support as we wanted	1
Yes, we got some support but not as much as we wanted	2
No, although we tried to get more	3
No, but we did not ask for more help	4
We did not need any help	5

**A12** Overall do you feel that you and your family got as much help and support from **social services**, such as home care workers, as you wanted when caring for him? (Please circle one option)

Yes, we got as much support as we wanted	1
Yes, we got some support but not as much as we wanted	2
No, although we tried to get more	3
No, but we did not ask for more help	4
We did not need any help	5



## Section B: GPs or Family Doctors

This section of the questionnaire concerns **GPs or family doctors** who visited the person you cared for at home, or in a nursing or residential home, in the **last three months** of life. These questions refer to visits during normal working hours.

**B1** If the doctor visited the person you cared for in the last three months of life, how easy or difficult was it to get the doctor to agree to come and visit? (Please circle one option):

Very easy	1	<b>Go to B2</b>
Fairly easy	2	<b>Go to B2</b>
Fairly difficult	3	<b>Go to B2</b>
Very difficult	4	<b>Go to B2</b>
Wanted the GPs to visit but they would not visit	5	<b>Go to Section C</b>
Not applicable, the doctors did not visit in the last three months, they were not needed	6	<b>Go to Section C</b>
Don't Know	7	<b>Go to Section C</b>

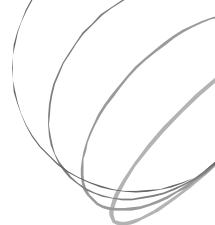
**B2** During these last three months, do you feel that the GPs had time to listen and discuss things with you? (Please circle one option):

Yes	1
No	2
Don't know	3

**B3** Were you able to discuss with the GPs any worries or fears you had about the condition, treatment or tests for the person you cared for? (Please circle one option):

I had no worries or fears to discuss	1
Yes, I discussed them as much as I wanted	2
Yes, I discussed them but not as much as I wanted	3
No, although I tried to discuss them	4
No, but I did not try to discuss them	5





## Section C: Nursing/ Residential Home Care

These questions are concerned with any time that the person you cared for may have spent in a **nursing or residential home** during the **last three months** of life. Please note **hospital / hospice care** is covered in Sections D and E.

**C1** In the last three months of life, did the person you cared for have a health problem for which he needed care in a nursing or residential home? (Please circle one option):

Yes	1	<b>Go to C2</b>
No	2	<b>Go to Section D</b>

**C2** How much of a problem, if any, was it to get nursing or residential home care? (Please circle one option):

A big problem	1
A small problem	2
Not a problem	3
Don't know	4

**C3** During his stay in the nursing or residential home, do you feel that staff had time to listen and discuss things with you? (Please circle one option):

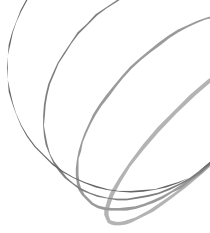
Yes	1
No	2
Don't know	3

**C4** During his stay in the nursing or residential home was there enough help available to meet personal care needs, such as bathing, dressing, help with eating, and going to the bathroom? (Please circle one option):

Yes	1
No	2
Don't know	3

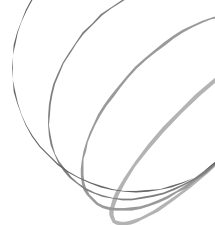
**C5** During the last three months of life while the person you cared for was in the nursing or residential home, if he had pain, did he have any treatment for his pain? (Please circle one option):

He had pain and received treatment for it	1	<b>Go to C6</b>
He had pain but did not receive treatment for it	2	<b>Go to Section D</b>
He did not have pain	3	<b>Go to Section D</b>
Don't know	4	<b>Go to Section D</b>



**C6** Did the treatment relieve his pain? (Please circle one option):

Completely all of the time	1
Completely some of the time	2
Partially	3
Not at all	4
Don't know	5



## Section D: Hospital Care

These questions are about the person's last overnight stay in **hospital**. If he did not stay in hospital for more than 24 hours in the last three months of life then please follow the instructions in D1.

**D1** Did the person you cared for stay in hospital, at any time during the last three months of life, for more than 24 hours? (Please circle one option):

Yes	1	<b>Go to D2</b>
No, not for more than 24 hours	2	<b>Go to Section E</b>
Don't know	3	<b>Go to Section E</b>

**D2** If 'Yes', what was the name of the last hospital in which he received care? (Please write in below)

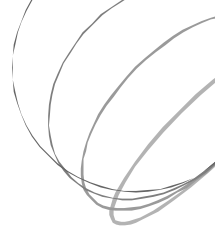
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**D3** Thinking about this last admission to hospital, do you feel that the person you cared for was discharged or transferred at the right time? (Please circle one option):

Yes, he was discharged or transferred at the right time	1
No, he was discharged or transferred too soon	2
No, he was discharged or transferred too late	3
He was not discharged, he died on this admission	4
Don't know	5

**D4** Were you involved in decisions about his treatment and care as much as you wanted? (Please circle one option):

Yes, I was involved as much as I wanted	1
No, I would have liked to be more involved	2
Don't know	3
Not applicable	4



**D5** During this hospital stay, did the hospital doctors and nurses explain his condition, treatment or tests in a way that you found easy or difficult to understand? (Please circle one option):

Very easy	1
Fairly easy	2
Fairly difficult	3
Very difficult	4
They did not explain his condition, treatment or tests to me	5
I never spoke with a doctor/nurse	6

**D6** During this hospital stay, was there enough help available to meet personal care needs, such as bathing, dressing, help with eating, and going to the bathroom? (Please circle one option):

Yes	1
No	2
Don't know	3

**D7** During this hospital stay, if he had pain, did he have any treatment for his pain? (Please circle one option)

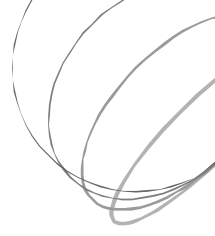
He had pain and received treatment for it	1	<b>Go to D8</b>
He had pain but did not receive treatment for it	2	<b>Go to D9</b>
He did not have pain	3	<b>Go to D9</b>
Don't know	4	<b>Go to D9</b>

**D8** Did the treatment relieve his pain? (Please circle one option):

Completely all of the time	1
Completely some of the time	2
Partially	3
Not at all	4
Don't know	5

**D9** Were you able to discuss with doctors, nurses or other hospital staff any worries or fears you had about the condition, treatment or tests for the person you cared for? (Please circle one option):

I had no worries or fears to discuss	1
Yes, I discussed them as much as I wanted	2
Yes, I discussed them but not as much as I wanted	3
No, although I tried to discuss them	4
No, but I did not try to discuss them	5



## Section E: Hospice Care

These questions are about the last admission to a **hospice**. If the last admission was for less than 24 hours, please answer these questions about a previous admission that was for **more than 24 hours**. If the person you cared for was never admitted to a hospice then please follow the instructions at E1

**E1** Did the person you cared for stay in a hospice or palliative care unit at any time during the last three months of life? (Please circle one option):

Yes	1	<b>Go to E2</b>
No, not for more than 24 hours	2	<b>Go to Section F</b>

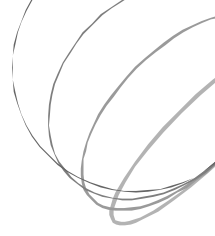
**E2** If ‘Yes’, what was the name of the last hospice or palliative care unit where he received care? (Please circle one option or write in below)

Accord Hospice, Paisley	1
Ardgowan Hospice, Greenock	2
Ayrshire Hospice, Ayr	3
Highland Hospice, Inverness	4
Marie Curie Hospice, Greater Glasgow and Clyde	5
Prince & Princess of Wales Hospice, Greater Glasgow and Clyde	6
Queen Margaret Hospital, Hospice Ward 16, Dunfermline	7
St Margaret of Scotland Hospice, Clydebank	8
St Vincent’s Hospice, Johnstone	9
Strathcarron Hospice, Denny	10
Victoria Hospice, (NHS Fife), Kirkcaldy	11
Macmillan Centre, Borders General Hospital	12
CHAS, Rachael House, Kinross	13
CHAS, Robin House, West Dunbartonshire	14
Waverley Care, Edinburgh	15
Other (please write in)	16

-----

**E3** Thinking about this last admission to hospice, do you feel he was discharged or transferred at the right time? (Please circle one option):

Yes, he was discharged or transferred at the right time	1
No, he was discharged or transferred too soon	2
No, he was discharged or transferred too late	3
He was not discharged, he died on this admission	4
Don’t know	5



**E4** During this stay, did the hospice doctors and nurses explain his condition, treatment or tests in a way that you found easy or difficult to understand? (Please circle one option):

Very easy	1
Fairly easy	2
Fairly difficult	3
Very difficult	4
They did not explain his condition, treatment or tests to me	5
I never spoke with a doctor/nurse	6

**E5** During this stay, was there enough help available to meet personal care needs, such as bathing, dressing, help with eating, and going to the bathroom? (Please circle one option):

Yes	1
No	2
Don't know	3

**E6** During this stay, if he had pain, did he have any treatment for his pain? (Please circle one option):

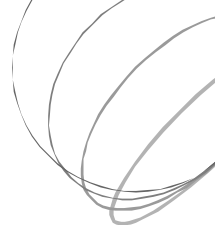
He had pain and received treatment for it	1	<b>Go to E7</b>
He had pain but did not receive treatment for it	2	<b>Go to E8</b>
He did not have pain	3	<b>Go to E8</b>
Don't know	4	<b>Go to E8</b>

**E7** Did the treatment relieve his pain? (Please circle one option):

Completely all of the time	1
Completely some of the time	2
Partially	3
Not at all	4
Don't know	5

**E8** Were you able to discuss with doctors, nurses or other hospice staff any worries or fears you might have had about the condition, treatment or tests for the person you cared for? (Please circle one option):

I had no worries or fears to discuss	1
Yes, I discussed them as much as I wanted	2
Yes, I discussed them but not as much as I wanted	3
No, although I tried to discuss them	4
No, but I did not try to discuss them	5



## Section F: Out-of-hours Services

The following questions are about **out-of-hours services** received in the **last three months of life**. This means services in the evenings, overnight, at weekends and public holidays, when the GP surgery is closed.

**F1** In the last three months, did you or the person you cared for need to contact out-of-hours services in relation to his illness?

Yes	1	<b>Go to F2</b>
No	2	<b>Go to Section G</b>
Don't know	3	<b>Go to Section G</b>

**F2** What services did you contact? (Please circle all options that apply)

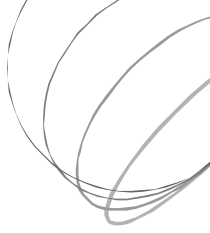
NHS 24	1
GP directly	2
Community nurse directly	3
Hospital ward	4
Hospice	5
Dialled 999 for ambulance	6
Other (please write in)	7

-----

**F3** What happened as a result of this contact? (Please circle all options that apply)

Advice was given on the telephone	1
A GP visited the house	2
A nurse visited the house	3
He was sent to hospital but not kept in	4
He was admitted to hospital or hospice	5
Other (please write in)	6

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**F4** How satisfied were you and the person you cared for with the response from out-of-hours services? (Please circle one option)

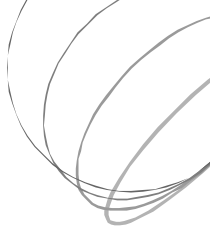
Completely satisfied	1
Reasonably satisfied	2
Partially satisfied	3
Completely dissatisfied	4
Don't know	5

**F4b** Please comment here, if you want to:

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## Section G: Respite Care

The following questions are about **respite care**. By respite care we mean care that the person received during the **last three months** which was mainly to give the carer and/or family a rest or break.

**G1** Did any of the following apply during the last three months? (Please circle one option)

We asked for respite care and got it when we wanted it	1	<b>Go to G2</b>
We asked for respite care and had to wait to get it	2	<b>Go to G2</b>
We asked for respite care but were unable to get it	3	<b>Go to Section H</b>
We did not ask for respite care because we did not need it	4	<b>Go to Section H</b>
We did not ask for respite care because we did not know that it might be available	5	<b>Go to Section H</b>

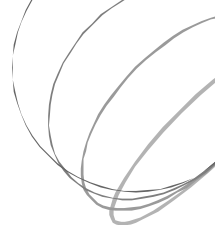
**G2** Where did he go for respite care during the last three months? (Please circle all options that apply)

He was admitted to hospital	1
He was admitted to hospice	2
He went to a day unit	3
He went to a nursing home	4
Someone came to the house so the carer/family could go out	5
Other (please write in)	6

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**G3** Was the respite care sufficient? (Please circle one option)

Yes, we received as much respite care as we needed	1
No, we did not receive as much respite care as we needed	2



## Section H: Last three days of life

These questions are concerned with experiences in the **last three days** of life and the care received during this time. If the person you cared for was in more than one place, please answer the following questions about the place he **spent the most time**.

**H1.** During the last three days was he mostly? (Please circle one option):

At home	1
In a nursing or residential home	2
In hospital	3
In a hospice	4
Other (please write in)	5

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**H2** During the last three days, were you involved in decisions about his treatment and care as much as you wanted? (Please circle one option):

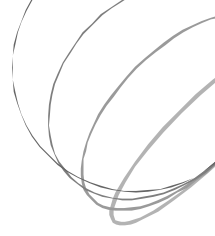
Involved as much as I wanted	1
Would have liked to be more involved	2
Don't know	3
Not applicable	4

**H3** During these last three days, was there enough help available to meet personal care needs, such as bathing, dressing, help with eating, and going to the bathroom? (Please circle one option):

Yes	1
No	2
Don't know	3

**H4** During these last three days, was there enough help with nursing care, such as getting dressings changed and with medication? (Please circle one option):

Yes	1
No	2
Don't know	3
Not applicable	4

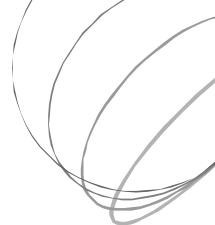


**H5** During these last three days, if he had pain, did he have any treatment for his pain? (Please circle one option):

He had pain and received treatment for it	1	<b>Go to H6</b>
He had pain but did not receive treatment for it	2	<b>Go to Section I</b>
He did not have pain	3	<b>Go to Section I</b>
Don't know	4	<b>Go to Section I</b>

**H6** Did the treatment relieve his pain, (Please circle one option):

Completely all of the time	1
Completely some of the time	2
Partially	3
Not at all	4
Don't know	5



## Section I: Other Care Issues

The following questions are about other issues surrounding the **services and support received by** person you cared for.

### I1. Where did the person you cared for die?

In his own home	1
In the home of another family member or friend	2
Hospital	3
Hospice	4
Residential / nursing home	5
On the way to hospital / hospice	6
Other (please write in)	7

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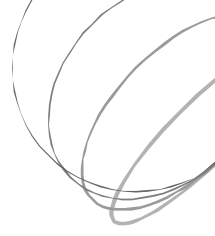
### I2. On balance, do you feel that he died in the right place? (Please circle one option)

Yes, it was the right place	1	Go to I4
No, it was not the right place	2	Go to I3
Don't know	3	Go to I4

### I3. If 'No' was it because:

It was not where he wanted to die	1
The care he received there was poor	2
He was too far away from family and friends	3
Not applicable	4
Other please write in)	5

-----



**I4** Do you feel that there were any ways in which **health services** could have helped to make the end of life easier for him? (Please circle one option)

Yes	1
No	2
Don't know	3

**I4b** Please comment here, if you want to:

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**I5** Do you feel that there were any ways in which **social services** could have helped to make the end of life easier for him? (Please circle one option)

Yes	1
No	2
Don't know	3

**I5b** Please comment here, if you want to:

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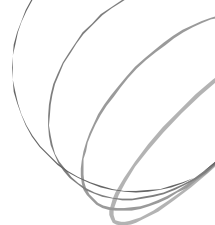
**I6** How difficult was it for the person you cared for and his family to cover the cost of care at the end of his life? (Please circle one option)

Very difficult	1
Somewhat difficult	2
Not very difficult	3
Not difficult at all	4
Don't know	5

**I7** In which settings, if any, were his spiritual needs looked after? (Please circle all options that apply)

At home	1
At the GPs / family doctor	2
At the nursing / residential home	3
At the hospital	4
At the hospice	5
Don't know	6
None	7
Other (please write in)	8

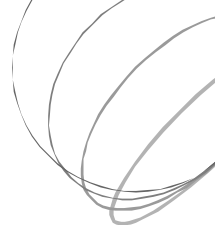
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**I8** In which settings, if any, were his emotional needs looked after? (Please circle all options that apply)

At home	1
At the GPs / family doctor	2
At the nursing / residential home	3
At the hospital	4
At the hospice	5
Don't know	6
None	7
Other (please write in)	8

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**If you have any additional comments, please write them in the space below**

## **Thank-you**

Thank-you very much for taking the time to complete this questionnaire. Your views are an important part of this work, which will influence how services are provided to support ill people and their carers. Audit Scotland will publish its report in summer 2008. If you would like to receive a copy of the report please contact Lilian Brown on 0845 1461010.

Please now put your completed questionnaire in the reply paid envelope and return it to us. If you have misplaced the envelope, please use this freepost address – no need for a stamp.

George Street Research Ltd  
FREEPOST EH1946  
EDINBURGH  
EH1 0BR

***Once again, thank you very much for your time***

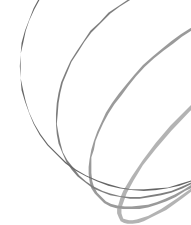
# Appendix 4. The ACORN Consumer Classification

Category	% UK POP	Group	% UK POP	Type	% UK POP		
1	Wealthy Achievers	A	Wealthy Executives	8.6	1	Wealthy mature professionals, large houses	1.7
					2	Wealthy working families with mortgages	1.5
					3	Villages with wealthy commuters	2.7
					4	Well-off managers, larger houses	2.6
		B	Affluent Greys	7.7	5	Older affluent professionals	1.8
					6	Farming communities	2.0
					7	Old people, detached homes	1.9
					8	Mature couples, smaller detached homes	2.0
		C	Flourishing Families	8.8	9	Older families, prosperous suburbs	2.1
					10	Well-off working families with mortgages	2.3
					11	Well-off managers, detached houses	3.7
					12	Large families and houses in rural areas	0.6
2	Urban Prosperity	D	Prosperous Professionals	2.2	13	Well-off professionals, larger houses and converted flats	0.9
					14	Older professionals in suburban houses and apartments	1.4
		E	Educated Urbanites	4.6	15	Affluent urban professionals, flats	1.1
					16	Prosperous young professionals, flats	0.9
					17	Young educated workers, flats	0.6
					18	Multi-ethnic young, converted flats	1.1
					19	Suburban privately renting professionals	0.9
		F	Aspiring Singles	3.9	20	Student flats and cosmopolitan sharers	0.6
					21	Singles and sharers, multi-ethnic areas	1.6
					22	Low income singles, small rented flats	1.2
					23	Student terraces	0.4
					24	Young couples, flats and terraces	1.0
25	White-collar singles/sharers, terraces				1.4		
3	Comfortably Off	G	Starting Out	2.5	26	Younger white-collar couples with mortgages	1.9
					27	Middle income, home owning areas	2.9
		H	Secure Families	15.5	28	Working families with mortgages	2.6
					29	Mature families in suburban semis	3.3
					30	Established home owning workers	3.6
					31	Home owning Asian family areas	1.1
					32	Retired home owners	0.9
		I	Settled Suburbia	6	33	Middle income, older couples	3.0
					34	Lower incomes, older people, semis	2.1
					35	Elderly singles, purpose built flats	0.7
		J	Prudent Pensioners	2.6	36	Older people, flats	1.9
					K	Asian Communities	2.5
38	Low income Asian families	1.1					
4	Moderate Means	L	Post-Industrial Families	15.5	39	Skilled older families, terraces	2.8
					40	Young working families	2.1
		M	Blue-collar Roots	6	41	Skilled workers, semis and terraces	3.3
					42	Home owning families, terraces	2.8
					43	Older people, rented terraces	1.8
					44	Low income larger families, semis	3.3
5	Hard-Pressed	N	Struggling Families	14.1	45	Low income, older people, smaller semis	3.0
					46	Low income, routine jobs, terraces and flats	1.4
					47	Low income families, terraced estates	2.6
					48	Families and single parents, semis and terraces	2.1
					48	Large families and single parents, many children	1.7
					48	Large families and single parents, many children	1.7
		O	Burdened Singles	4.5	50	Single elderly people, council flats	1.8
					51	Single parents and pensioners, council terraces	1.9
					52	Families and single parents, council flats	0.8
		P	High-Rise Hardship	1.6	53	Old people, many high-rise flats	0.8
					54	Singles and single parents, high-rise estates	0.9
		Q	Inner City Adversity	2.1	55	Multi-ethnic purpose built estates	1.1
56	Multi-ethnic, crowded flats				1.1		
		U	Unclassified	0.3	57	Mainly communal population	0.3



# Appendix 5. International Classification of Diseases and Related Health Problems, Tenth Revision (ICD10)

<b>Cancer</b>	2	Neoplasms
<b>All organ failure</b>	3	Diseases of the blood and blood-forming organs and certain disorders involving the immune mechanism
	9	Diseases of the circulatory system
	10	Diseases of the respiratory system
	11	Diseases of the digestive system
	13	Diseases of the musculoskeletal system and connective tissue
	14	Diseases of the genitourinary system
<b>All neurological conditions</b>	5	Mental and behavioural disorders
	6	Diseases of the nervous system
<b>Total other</b>	1	Certain infectious and parasitic diseases
	4	Endocrine, nutritional and metabolic diseases
	7	Diseases of the eye and adnexa
	8	Diseases of the ear and mastoid process
	12	Diseases of the skin and subcutaneous tissue



## Appendix 6. Hospitals cited at question D2

Adamson Hospital, Cupar
Beatson West of Scotland Cancer Centre, Gartnavel General Hospital
Belford Hospital, Fort William
Borders General Hospital, Melrose
Caithness General Hospital, Wick
Dunoon General Hospital
Gartnavel General Hospital
Glasgow Royal Infirmary
Glenrothes Hospital
Hawick Community Hospital
Hay Lodge Hospital, Peebles
Inverclyde Royal Hospital, Greenock
Kelso Cottage Hospital
Lorn & Islands District General Hospital, Oban
Ninewells Hospital, Dundee
Queen Margaret Hospital, Dunfermline
Raigmore Hospital, Inverness
Royal Alexandra Hospital, Paisley
Royal Infirmary of Edinburgh
St. Andrews Memorial Hospital, St. Andrews
Southern General Hospital, Glasgow
Stobhill Hospital, Glasgow
Vale of Leven Hospital, Alexandria
Victoria Hospital, Kirkcaldy
Victoria Hospital, Rothesay, Isle of Bute
Victoria Infirmary, Glasgow
Western General Hospital, Edinburgh
Western Infirmary, Glasgow
Other hospital in NHS Greater Glasgow and Clyde
Other hospital in NHS Fife
Other hospital in NHS Borders
Other hospital in NHS Highland
Other hospital in Scotland
Other hospital in England
Not clear (not clear which hospital was last or full name of hospital not given)

# Review of palliative care services in Scotland

## Report supplement: Survey of bereaved families and friends

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