Health and Sport Committee

We need to talk about palliative care
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Health and Sport Committee

We need to talk about palliative care, 15th Report, 2015 (Session 4)
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**Note:** The membership of the Committee changed during the period covered by this report, as follows:

Malcolm Chisholm replaced Richard Simpson on 2 September.
Foreword

Benjamin Franklin said that “In this world nothing can be said to be certain, except death and taxes”. The latter is something that we as politicians have no difficulty discussing at the dispatch boxes. Death and the provision of care and support for those who are dying including the issue of palliative care, however, is a topic in which we are far more reticent and less willing to debate. The politician’s reluctance merely mirrors a wider societal problem with discussing how we ensure we live well when we are dying.

Increased life expectancy is to be celebrated, however it means we are no longer exposed to death in the same way. Dying has become an increasingly medicalised process which has removed the sick and dying from our homes to the medical ward and care home. This has led to the issue of death and provision of palliative care as being something occurring ‘off stage’ a less visible and less integral part of our day to day lives. As Atul Gawande details in his book “Being Mortal” as medical advances push the boundaries of survival further each year; we have become profoundly detached from the reality of being mortal.

The Committee’s interest in the issue of palliative care stems from a keenness to place the issue centre stage. Palliative care should be compassionate and coordinated holistic care which involves ongoing sensitive communication with individuals involved in decisions about their treatment and care package. This inquiry has aimed to shed a light on who is needing palliative care, whether they are receiving it and how appropriate the care provided is for the individual.

Introduction

1. In January 2015 the Committee agreed to hold an inquiry into palliative care. This decision was taken following the emergence of the importance of Palliative Care in the scrutiny of the Assisted Suicide (Scotland) Bill and the Scottish Government’s announcement of the development of a new Strategic Framework. The Committee agreed that it would be beneficial if this report could help inform the new Framework.

2. At oral evidence sessions on 28 April and 2 June 2015 the Committee heard from:
   - The Scottish Government
   - Care Inspectorate
   - Scottish Public Services Ombudsman
   - Healthcare Improvement Scotland

3. These evidence sessions were carried out to help provide an overview of the current system and to help shape the Committee’s approach to the inquiry.
4. On 2 July 2015 the Committee visited the Marie Curie Hospice in Glasgow where they met with patients and staff and launched the inquiry – ‘We need to talk about Palliative Care’. The remit of the inquiry is to look into access to palliative care [and where any barriers currently exist], understand the initial conversation around palliative care and also undertake some focussed research into international comparisons of measurement of data used in palliative care.

5. The same day, the Committee also launched its call for written views\(^3\) which ran until 12 August 2015 and received 57 responses\(^4\).

6. Committee members also visited Children’s Hospice Association Scotland Rachel House, Kinross and Ardgowan Hospice, Greenock to hear from healthcare professionals, volunteers, service users and their families. Oral evidence sessions were held on 22 and 29 September 2015.

7. A full list of those who gave evidence to the Committee can be found at Annexe A. The Committee thanks all those who have provided evidence as part of the inquiry. The Committee especially wishes to acknowledge its appreciation to those who shared their own experiences of a loved one or patients palliative care. These are sensitive and often difficult issues to discuss and we are grateful for the eloquent and informative evidence provided.

8. The Health and Sport Committee also commissioned research on international comparisons of measurement of data used in palliative and end of life care. The research aimed to explore which indicators were used to measure the access to and quality of palliative and end of life care in other countries. It also considered
which indicators have proven effective and why, based on international experiences and research. The research was to focus on recommendations made in published research and literature.

9. The research for the Committee was produced by Professor David Clark, Wellcome Trust Investigator, School of Interdisciplinary Studies, University of Glasgow.

10. Professor Clark’s report ‘International comparisons in palliative care provisions: what can the indicators tell us?’ was published on 15 September 2015. Professor Clark appeared before the Committee on that date to discuss his report. We thank Professor Clark for his informative report which helped us to establish the base line for palliative care provision in Scotland as compared to international experiences.

11. The Cabinet Secretary for Health, Wellbeing and Sport wrote to the Committee on 6 October 2015 welcoming the report prepared by Professor Clark and the recommendations made in it. The Cabinet Secretary advised that the Strategic Framework for Action for Palliative and End of Life Care is currently being developed and will be published towards the end of the year. This will include a focus on the development of ways to better describe service provision and the development of measures to demonstrate the impact of palliative and end of life care on key outcomes.

Background

Living and Dying Well

12. In October 2008 the Scottish Government published ‘Living and Dying Well’, its action plan for ensuring that palliative and end of life care was available to all people in Scotland with life-limiting conditions. ‘Living and Dying Well’ sought to “ensure that good palliative and end of life care was available for all patients and families who needed it in a consistent, comprehensive, appropriate manner across all care settings in Scotland.” The Government’s stated aim was “to ensure that palliative and end of life care in Scotland is of high quality and is continuously improving” and that palliative and end of life care would be: patient centred; safe; effective; efficient; equitable; and timely. ‘Living and Dying Well’ updates and progress reports were published in 2011 and 2012.

Palliative Care (Scotland) Bill

13. The Palliative Care (Scotland) Bill was introduced by Gil Paterson MSP on 1 June 2010, was considered at Stage 1 by the session 3 Health and Sport Committee but withdrawn in December 2010. Its objectives were to secure access to palliative care (including end of life care) for everyone in Scotland with a progressive life-limiting condition and their family members.
14. In its report on the Palliative Care (Scotland) Bill\textsuperscript{11} at stage 1, the session 3 Health and Sport Committee generally agreed that palliative care should be given more priority. However there were a number of concerns, particularly that “the focus and progress on delivery of ‘Living and Dying Well’ might be lost”. Members were convinced that good progress was being made under the strategic direction set by ‘Living and Dying Well’, and that this should be fully implemented and analysed before considering whether or not there was a need for legislation. However, a commitment was sought from the Scottish Government that it would establish a suite of appropriate indicators by April 2011 to allow for the monitoring and reporting of progress against the action points in ‘Living and Dying Well’. Healthcare Improvement Scotland published Palliative and end of life care indicators in March 2013.

15. Four palliative and end of life care indicators were developed:

- Increase in the number of people with palliative and end of life care needs who are identified
- Increase in the number of people with palliative and end of life care needs who are assessed and have a care plan
- Increase in the number of electronic palliative care summaries accessed
- Place of death

**Assisted Suicide (Scotland) Bill**

16. The Assisted Suicide (Scotland) Bill\textsuperscript{12} was introduced by Margo MacDonald MSP on 13 November 2013. The objective of the Bill was to “provide a means for certain people who are approaching the end of their lives to seek assistance to end their lives at a time of their own choosing, and to provide protection in law for those providing that assistance.”\textsuperscript{13}

17. The Bill was considered at Stage 1 by the Health and Sport Committee and the Stage 1 debate took place on 27 May 2015. The Bill fell following this debate.

18. As this Bill was considered the issue of palliative care arose numerous times. Some of the issues raised were:

- the importance of prioritising wide access to good palliative care
- good palliative care is care that responds to “physical…emotional and spiritual needs of people coming to the ends of their lives”
- palliative care often comes much too close to the end of life when it could have benefited from being delivered much earlier

19. This led to the Committees Stage 1 report noting
that some witnesses consider that the introduction of lawful assisted suicide would be liable to undermine the provision of palliative care. Nevertheless, the Committee is agreed that, regardless of whether the Bill progresses beyond Stage 1, there is a need for a thorough investigation and scrutiny of current provision and future plans for palliative care in Scotland.

Guidelines and Strategic Framework

Guidelines

20. In November 2014, a new set of palliative care guidelines were published by NHS Scotland and the Scottish Partnership for Palliative Care. A National statement and guidance on ‘Caring for people in the last days and hours of life’ was published by the Scottish Government in December 2014.

Strategic Framework

21. The Scottish Government has committed to develop a Strategic Framework for Palliative and End of Life Care by the end of 2015. This aims to provide support to improvements in the delivery of high quality palliative and end of life care for all ages and clinical conditions (including babies, children and young people). The development of the Strategic Framework will be linked to on-going work to review the narrative for the 2020 Vision for Health and Social Care.

Palliative and end of life care National Advisory Group

22. A new Palliative and end of life care National Advisory Group, supported by a wider stakeholder group (facilitated by the Scottish Partnership for Palliative Care) was established in 2014 and overseen by a National Clinical Lead for Palliative Care. Its work supports the implementation of the national plan and allows best practice evaluation of the new measures. Professor White, Chair of the National Advisory Group, told the Committee that although specialist palliative care is a service, palliative care is a dimension of care and not always a service as such, so “We recognise the need to have discussions with all the groups…about the really quite tricky issue of how we capture a fairly complex set of outcomes that span quality of life and physical, social and psychological outcomes”.

Types of Palliative Care

23. Palliative and end of life services tend to be organised according to whether they are specialist or generalist services.

Specialist palliative and end of life services

24. Specialist services are provided by multidisciplinary teams, who have undergone recognised specialist palliative care training. These teams work in partnership,
often with those providing generalist palliative and end of life care, ensuring that the complex needs of patients and their families are met. The aim of this care is to provide physical, psychological, social and emotional support, involving practitioners with a broad range of skills. It can be accessed in a number of care settings including acute hospitals, specialist units, hospices, the person’s own home and other community settings. The Scottish Government notes that core clinical palliative and end of life care services should include:

- 24 hour access to in-patient care facilities for the purposes of symptom management, rehabilitation and terminal care, which includes specialist medical and adequate specialist nursing cover

- 24 hour telephone advice and support services for healthcare professionals, patients and carers

- Day services provided by an out-patient model or day hospice model where patients attend for a determined part of the day

- Formalised arrangements for specialist input to local and community hospitals

25. It adds that the core team should comprise dedicated sessional input from: chaplains, doctors, nurses, occupational therapists, pharmacists, physiotherapists, and, social workers. Many specialist services are provided by the independent voluntary sector through hospices and other third sector organisations such as Marie Curie and Macmillan.

**Generalist palliative and end of life services**

26. General palliative and end of life care can also be delivered in a variety of settings, but is delivered by generalists professionals, such as GPs, community nurses, nurses and doctors from other specialties, allied health professionals, social workers and social carers, as well as the person’s own carer. SPPC states that generalist palliative and end of life care is based on the understanding and practice of a number of key principles:  

- a focus on quality of life which includes good symptom control

- a whole person approach which takes into account the person’s past life experience and current situation

- care which encompasses both the person with the life-threatening illness and those that matter to that person, with a respect for patient choice and an emphasis on open and sensitive communication.
Definition

What is palliative care?

28. The Committee heard from various witnesses that there were numerous definitions for palliative care, and differences between the definitions of adult palliative care and children’s palliative care.

29. Professor Clark advised during his evidence session “that a recent systematic review of definitions of palliative care in English and German came up with 56 variants”. 18

Palliative care for adults

30. There are a range of definitions available that describe the delivery of palliative and end of life care. However, most, including that used in Scotland, are in line with that of the World Health Organization (WHO):

“Palliative care is 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.” 19

31. This overall WHO definition clarifies that palliative care is:

• provides relief from pain and other distressing symptoms;
• affirms life and regards dying as a normal process;
• intends neither to hasten or postpone death;
• integrates the psychological and spiritual aspects of patient care;
• offers a support system to help patients live as actively as possible until death;
• offers a support system to help the family cope during the patients illness and in their own bereavement;
• uses a team approach to address the needs of patients and their families, including bereavement counselling, if indicated;
• will enhance quality of life, and may also positively influence the course of illness;
• is applicable early in the course of illness, in conjunction with other therapies that are intended to prolong life, such as chemotherapy or radiation therapy, and includes those investigations needed to better understand and manage distressing clinical complications.
32. The WHO definition goes on to state that it follows that palliative care can be provided at any stage following diagnosis of a relevant illness or condition, and not solely in the last few days, weeks or months of life. It is for this reason that the term ‘palliative and end of life care’ is used, so as to distinguish between the different stages of a person’s illness or condition.

33. Traditionally, palliative and end of life care has been associated with cancer patients, but it has become accepted that it should also be a routine part of care for those living with and dying from a wide variety of non-malignant conditions, including dementia, heart failure, neurological conditions (e.g. motor neuron disease) and renal failure.

34. The General Medical Council (GMC) defines palliative care as “The holistic care of patients with advanced, progressive, incurable illness, focused on the management of a patient’s pain and other distressing symptoms and the provision of psychological, social and spiritual support to patients and their family. Palliative care is not dependent on diagnosis or prognosis, and can be provided at any stage of a patient’s illness, not only in the last few days of life. The objective is to support patients to live as well as possible until they die and to die with dignity.”

35. The Scottish Partnership for Palliative Care (SPPC) defines it as “the care that is given when cure is not possible. The word comes from the Latin 'palliatus' (covered or hidden with a cloak) and is used to mean 'relieving without curing'.”

Palliative care for children

36. The definition of palliative care for children, whilst following the similar principles, is slightly different. WHO’s definition states—

Palliative care for children represents a special, albeit closely related field to adult palliative care. WHO’s definition of palliative care appropriate for children and their families is as follows; the principles apply to other paediatric chronic disorders (WHO; 1998a):

- palliative care for children is the active total care of the child's body, mind and spirit, and also involves giving support to the family.
- it begins when illness is diagnosed, and continues regardless of whether or not a child receives treatment directed at the disease.
- health providers must evaluate and alleviate a child's physical, psychological, and social distress.
- effective palliative care requires a broad multidisciplinary approach that includes the family and makes use of available community resources; it can be successfully implemented even if resources are limited.
- it can be provided in tertiary care facilities, in community health centres and even in children's homes.
37. The Royal College of General Practitioners Scotland (RCGPS)\textsuperscript{24}, Health and Social Care Alliance Scotland (the ALLIANCE)\textsuperscript{25} and Scottish Independent Advocacy Alliance\textsuperscript{26} discussed the importance of definitions in their written submissions. They highlight that there appear to be many definitions of palliative care, specialist palliative care, general palliative care and end of life care with the distinction between them being unclear. These terms are often used interchangeably but mean different things. The SPPC\textsuperscript{27} draw attention to professional and public beliefs that palliative care is terminal care only of relevance and benefit shortly before death (rather than for symptom management and to address the side-effects of treatment) and primarily of relevance to people with cancer.

38. The SPPC considers that much of the care that people receive when their health is deteriorating could be termed general palliative care, being provided by health and social care professionals to people living in the community, in care homes and in hospitals. The SPPC also considers that specialist palliative care is for people with more challenging palliative care needs such as complex pain management or psychological support. This is provided by specially trained multi-professional specialist palliative care teams who are generally based in a hospice or a NHS specialist palliative care unit, but whose expertise should be accessible from any care setting. The SPPC highlights that although the care and expertise of formal services is essential, it is important to remember that most care is provided by family, friends, carers and the community.

39. The RCGPS draws attention to the General Medical Council, in its publication ‘Treatment and Care towards the End of Life’, where it states that “patients are approaching the end of life when they are likely to die within the next 12 months” and end of life care is aimed at these individuals.

40. Throughout the oral evidence sessions the Committee also heard about the differences in the definitions of palliative care. The SPPC stated:

\begin{quote}
That lack of clarity around terminology is a problem...We said that one way of thinking about palliative care is to think about providing good holistic care to people whose health is in irreversible decline, whose lives are coming to inevitable close, or who have received a diagnosis in which their mortality will impact on decisions that they make about what their priorities are.\textsuperscript{28}
\end{quote}

41. One area that came up often in oral evidence was the need to better frame the thinking around palliative care. It should not be regarded only in terms of being a matter of generalist or specialist palliative care but rather being about the person, what their needs and circumstances are, and what matters to them.

42. Professor Clark, in his report to the Committee, contended that “Definitional problems continue to inhibit clarity of thought and action in the field. It is not recommended however that Scotland should depart from the 2002 WHO definition of palliative care”\textsuperscript{29}. 
43. NHS Grampian, during oral evidence, mentioned Professor Clark's statement and commented that although they believe that certain definitions are necessary for generalist palliative care and perhaps specialist palliative care, what people require is appropriate care at specific points throughout their illness. However they believe that need, not diagnosis was the prime mover for care.

44. The RCGPS argued that:

> there are only two things that separate palliative care from good care. The first is the fact that it is an enormous deal, because you only do it once... Other than that, the only thing that separates palliative care from good care... is that, as one fails, the ceilings of what one is offered and what is considered appropriate begin to lower... apart from the enormity of the end of life situation itself, the gradual lowering of the ceilings of treatment or intervention is the only thing that separates palliative care from good care.

45. The Committee recognises that for some witnesses the lack of a single definition for palliative care may cause issues such as providing a clear understanding of when such care should be offered or provided. However for other witnesses providing a single definition was seen as detrimental to the aim of ensuring that good palliative care is provided based on peoples' needs.

46. The Committee therefore recommends that the strategic framework should set out clearly core principles upon which palliative care in Scotland is to be provided. We also request that the Scottish Government considers whether the framework should provide definitions of 'palliative care' (such as that provided by the WHO) and 'end of life' care.

47. The Committee agrees that palliative care should be 'person-centred' and that palliative and end of life care should encompass more than just specialist settings. A great deal of palliative care is being carried out in generalist settings and encompasses holistic treatments. Palliative care should be focused on the individual's needs at points throughout their illness.

48. The Committee seeks clarification from the Scottish Government on what steps it will take to ensure such a system is available in Scotland and how the Framework will enable palliative care to be 'person-centred'.
Improving data collection

49. Professor Clark highlighted in his report three sets of palliative care indicators:

- Indicators of **specific resources** (or inputs) that support the delivery of palliative care – services, beds, staff, drug availability, training, policies, research infrastructure, guidelines, funding mechanisms, professional accreditation

- Indicators of **need** or **process** that tell us something about the requirement for palliative care or the ways in which it is being organised and delivered

- Indicators of **quality** (or outcomes) that tell us something about how well palliative care is being delivered – audits, evaluation studies, quality markers, service user feedback and results from randomised trials.

50. At present, the UK ranks top in all of the key studies of palliative care development around the world. This is in relation to organisation and delivery of palliative care. However, it is not possible to breakdown the Scottish context within this data, since palliative care in Scotland is only a constituent part of the data for the UK as a whole.

51. On 6 October 2015 the Economist Intelligence Unit published a report stating that the UK ranks first in the 2015 Quality of Death Index, a measure of the quality of palliative care in 80 countries around the world. The report states that the UK’s ranking is due to comprehensive national policies, the extensive integration of palliative care into the National Health Service, a strong hospice movement, and deep community engagement on the issue.

52. One of Professor Clark’s key findings was that a serious information deficit needs to be filled on data relating to the provision of palliative care in Scotland – starting with inputs and resources, but also including needs analysis, access, quality and outcomes. The House of Commons Health Committee’s recent End of Life Care Report also recommended the development of outcome measures for palliative care. It stipulated that these must be properly evaluated and funded in order to improve the quality of care for people at the end of life.

53. Many of the written submissions that the Committee received highlighted that Scotland does not currently collect and analyse enough data to show the provision of palliative care across the country or to evidence the development of services or the improvement of access to palliative care and the level of services provided.

54. Professor Clark highlighted in his report that one of the main issues around palliative care indicators was the problem of identifying those who might benefit from palliative care. His report stated ‘in Scotland on a given day, 28-9 per cent of the hospital population (in 2010 and in 2013) were in the last year of life and that 8-9 per cent of the hospital population on any given day will die before they leave’.
55. The Committee is concerned by the findings of the research it commissioned that there is a serious information deficit which needs to be filled by data relating to the provision of palliative care.

56. Many of the written submissions also revealed that there are gaps in both qualitative and quantitative data. The Committee is concerned by the lack of data and how this limits the ability to assess the effectiveness of current palliative care provision.

57. The Committee recognises the importance of collecting data in being able to measure the effectiveness and quality of palliative care. Data collection can also enable identification of where service provision needs to improve or where there are gaps in services. Data also supports the identification of good practice.

58. The Committee believes that for the Scottish Government to be able to assess whether it’s forthcoming strategic framework and any investment in palliative care provision is effective it needs to be able to assess the services provided and the quality of care and treatment. Collecting appropriate data is a vital component to being able to conduct this assessment.

59. The Committee welcomes the Scottish Government acknowledgement that more needs to be done to identify those with palliative care needs. The Committee therefore recommends that the Scottish Government include a range of input and outcome indicators in its Framework to assess whether good quality palliative and end of life care is being provided and to assess the availability of palliative care.

Specific resources – inputs

60. As part of its recent scrutiny of NHS Boards budgets 2015-16, the Committee asked for information on spending for palliative and end of life care.

61. As discussed in the Committee’s NHS boards budgets 2015-16 report, the quality and level of data provided by NHS boards in the survey responses on palliative and end of life care and hospice funding was mixed. A number of boards said that it was not possible for them to separate out general palliative care expenditure from other areas of spending. However, some boards did manage to provide an estimated figure for their spending on palliative and end of life care.

62. Various responders noted that it was a challenge to determine what services to include to measure the cost of palliative care provision. The Chief Executive of NHS Scotland also acknowledged that the way information was recorded at present made it difficult to identify palliative care spend.
63. NHS Dumfries and Galloway stated “We have included in the Dumfries and Galloway return the specialist services that we provide—specifically, the in-patient facility in the infirmary, which operates as our hospice, and the services that we commission through Marie Curie Cancer Care to supplement community support. You will find that an element of the role of all our community teams and district nursing teams is to support individuals who are at the end of life”.  

64. It was noted that although boards felt that increasing the percentage of people who spend the last six months of life at home or in a community was a useful indicator, the findings of the NHS board survey suggested that it had limited, if any, direct influence on budgetary decisions. A number of boards noted that it was a ‘crude’ measure as it did not take account of the quality of care patients received. NHS Tayside believed that a number of alternative performance measures, including percentage achieving preferred place of dying would be better.

65. The Committee considers it important to collect data on spend on palliative care as this helps identify which services are delivering value for health boards. This is even more important given the current financial climate.
66. Whilst the Committee recognises that there are challenges to measuring and collating palliative care spend at NHS board level we note that some health boards were able to provide such information, as evidenced during our NHS Boards budgets 2015-16 report.\(^1\) The Committee notes that it is not possible to establish whether all boards have reported according to common definitions.

67. The Committee believes that further steps could be taken by the Scottish Government to assist boards to consistently collect comparable information on their spending on palliative care. The Committee recommends as part of the strategic framework that the Scottish Government provides health boards with parameters in which to measure and quantify the services that are encompassed by palliative care, and their associated spend.

**Need or Process**

68. One of the issues highlighted to the Committee was the lack of data and information on the number of people who require and/or receive palliative care. Marie Curie highlighted that there are almost 12,000 people on the palliative care register but it is estimated that 40,000 people who needed palliative care will die each year.\(^37\)

69. CHAS advised the Committee that in order to gain a better understanding of the paediatric palliative care needs in Scotland, it had commissioned a research project, in partnership with the Scottish Government, led by Dr Lorna Fraser and Professor Bryony Beresford from University of York.

70. The research was published on 4 November 2015. The report found that the prevalence of babies, children and young people in Scotland with life-shortening conditions has risen from 4,334 in 2003-04 to 6,661 in 2013-14. The report states that there is a requirement for an increase in palliative care to meet the increasing need. The report recommends further improvements across the healthcare and social care sectors including:

- The under ones being a priority group for improved palliative care provision
- Future development of palliative care services to ensure services for babies, children and young people from areas of deprivation are prioritised, due to a higher prevalence of life-shortening conditions for those living in the most deprived areas

\(^{1}\) seven boards provided details of spending on general palliative care, nine boards gave details of existing and planned expenditure on specialist palliative care and four boards declined, with some stating that it was not possible to disaggregate palliative care from other funding streams.

[http://www.scottish.parliament.uk/S4_HealthandSportCommittee/Inquiries/NHS_Board_Survey_Analysis.pdf](http://www.scottish.parliament.uk/S4_HealthandSportCommittee/Inquiries/NHS_Board_Survey_Analysis.pdf)
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- Age specific palliative services to be developed for the 16-25 age group, as their needs are different to children and older adults with a life-shortening condition
- Specialist psychological and emotional care for all family members.\(^{38}\)

71. CHAS is in discussion with the Child and Maternal Health Department and Healthcare Quality and Strategy Directorate of Scottish Government about the implications of the research results.\(^{39}\)

72. Marie Curie also highlighted that quantitative data is needed to understand how many people need palliative care, when they get it, the kind of interventions that they receive and the outcomes. Data is also needed on the quality of that care.

73. During the evidence session to inform the inquiry into palliative care on the 28 April, the Scottish Government explained that in assessing the need for Palliative Care:

> We are absolutely committed to improving our ability to measure and present to this committee and others something more definitive in terms of numbers of people. It is likely to take some further time to get that right, though. We expect it to be in the strategic framework for action.\(^{40}\)

74. The Committee welcomes the steps taken by CHAS to commission research into the number and needs of children in Scotland requiring palliative care. The Committee asks the Scottish Government to confirm how it will use the findings of CHAS research to inform its strategic framework.

75. The Committee welcomes confirmation from the Scottish Government that they are committed to improving their ability to measure and provide more definitive information on the numbers of people requiring access to palliative care. We look forward to its forthcoming Framework setting out how it will assess the level of need for Palliative Care services as well as the numbers of people who then subsequently access such services.

Quality - outcomes

76. The Committee recognises that much of the data around palliative care is based on outcomes. Professor Clark highlighted that two ways that could be used to record outcomes better were the National Survey of Bereaved People, and the Views of Informal Carers – Evaluation of Services (VOICES\(^{41}\)). Professor Clark noted that VOICES was previously used locally in Scotland, but has not been used recently. VOICES has been adopted in England as the instrument for annual monitoring of satisfaction with care, as seen by the carer or relative of someone who has died recently and forms the core of the National Survey of Bereaved People.\(^{42}\)
77. The Committee received evidence supporting the use of qualitative data from palliative care service users and their families on the effectiveness of services. Some highlighted VOICES as such a tool for measuring outcomes.

78. During oral evidence NHS Education for Scotland stated:

> The national bereavement survey provides one way of looking at people’s needs and what individuals want. Professionals also have a perspective on what people need, which may or may not be what individuals want. Professionals could bring in things that families and relatives might not recognise, and they might pick up on different aspects.”

79. Similarly, the Association for Palliative Medicine of Great Britain and Ireland stated “I think that the data is very valuable, but let us not forget that it comes from a group of people who have had the burden of witness, and it is worth noting the extent to which they are dealing with their own loss and suffering”.

80. On 12 May 2015, during a members’ business debate on palliative and end-of-life care, the Minister for Sport, Health Improvement and Mental Health advised that:

> Marie Curie has rightly emphasised the importance of being able to have data and information to be able to describe progress. It is particularly interested in the views of informal carers for the evaluation of services—VOICES—survey in England. Our future plans, therefore, must include the enhancement of a national approach to measurement and monitoring. That includes a key indicator on end-of-life care as part of the requirements to measure improvements in health and wellbeing outcomes under health and social care integration”.

81. The Committee considers that families and service users have an important role to play in providing feedback on the quality and timeliness of palliative care and end of life service provision. It is important that, as well as being able to assess the inputs into palliative care with regards to services, an assessment of the quality of the services they actually provide is established.

82. The Committee therefore recommends that the strategic framework recognises the role of service users and their families in helping to improve the quality of palliative care service provision. One of the ways that this could be delivered is through the use of the VOICES survey which could be a useful tool for providing an assessment from families of their experiences of palliative and end of life care.
83. The Committee notes that the Minister for Sport, Health Improvement and Mental Health has previously indicated that the Scottish Government will encourage the local use of VOICES. The Committee would welcome the views of the Scottish Government on whether it intends to make the use of VOICES survey Scotland wide.

Helping the conversation

84. The Committee acknowledges that in general people do not like to talk about dying and that they find it difficult to talk about deteriorating health and death. Many respondents felt that currently many people are reluctant to discuss death, dying and loss – whether as individuals, professionals, family or friends – and that these kinds of conversations should be more normal, giving professionals and the public the confidence and support to be open about these issues. It was felt that a cultural shift is required in Scotland.

85. Scottish Care talked about the need to encourage people to regain ownership of dying. Previously it was the case that when someone knew they were dying they would come home (or to a relative’s home) to do so. This resulted in a first-hand experience of someone dying and was a normal part of family life. This made the discussion of dying much easier to have.
86. The Scottish Partnership for Palliative Care highlighted the importance of raising awareness of why being more open about dying might be of benefit to people themselves, and to their families and friends. It is important to understand the benefit of thinking ahead and planning a will, granting a power of attorney and having discussions with a GP about what preferences a person might have in terms of medical issues at the end of life.

87. Ownership of dying can be gained through various methods, some of which are mentioned above. East Dunbartonshire Council highlighted other means such as the use of social media and the internet. The charity CaringBridge has set up a page that allows individuals to set up a blog so that they can communicate with friends and family and others on the internet.

88. East Dunbartonshire Council also made the Committee aware of a community asset approach that they are working on with Macmillan Cancer Support. The website allows members of the public and service users to identify community facilities and services that are useful to people who are living with cancer or other long-term conditions and not just those at end of life. It helps them customise their support plans and help build networks.

**Good Life, Good Death, Good Grief**

89. Good Life, Good Death, Good Grief is an alliance that has linked up nearly 1,000 organisations and individuals looking to provide information and opportunities, shifting culture and normalising discussions around dying and the planning process.

90. The Scottish Partnership for Palliative Care gave Good Life, Good Death, Good Grief as a practical example of how the culture in Scotland can be changed to one where people are more open to discussing dying.

91. One of the organisations involved in Good Life, Good Death, Good Grief is Age Scotland. They have formed a partnership with a consortium of legal practices called Solicitors for Older People Scotland. The partnership arranged for a lawyer to attend some of Age Scotland’s lunch clubs across Scotland to do a presentation and to encourage discussion about legal planning. This helped to broach the subject of death in an easier and more approachable manner.

92. The Committee commends programmes such as Good Life, Good Death, Good Grief for helping to bring difficult conversations around death and dying into the fore and making these conversations more approachable. The Committee recognises the need for having a national (or ‘top-down’) approach to public health campaigns but also acknowledges the importance of local initiatives (‘bottom-up’) such as those mentioned in enabling conversations about death and dying to take place at a community level.
93. The Committee considers that there is a role for the Scottish Government to encourage a ‘bottom-up’ approach within local communities and asks for clarification of whether this will be supported within the strategic framework.

94. The Committee agrees that conversations around death and dying should become a usual part of life and not just discussed at the end of life.

95. The Committee considers it important that people are empowered to have discussions with health and social care professionals on palliative care and end of life care. The Committee asks the Scottish Government how it will use the Framework to help support discussions around death and dying and also raise the public profile about the need for such conversations.

**Who, what, where, when**

96. The Committee sought evidence on who was best placed to discuss palliative care needs, what needed to be discussed, where this discussion should take place and when the best time to discuss palliative care needs was.

97. The responses to this area of questioning were varied. The Royal College of Nursing Scotland (RCN) wrote that:

> The right time for individuals to initiate the conversation and the right time for professionals is not always the same. Professionals require the skills and sensitivity to create the conditions for individuals and their families to feel comfortable to discuss their choices as soon as possible after diagnosis. The sooner people discuss their wishes, fears and issues in an open and supportive way the better their outcomes.  

98. The RCN Scotland also feel that all health care staff should have basic palliative care skills at a generalist level to be able to have conversations about the care being provided. They also agree with supporting social care and third sector staff in discussing aspects of palliative care sensitively and with confidence.

99. South Lanarkshire Council state that the patient should be in control of deciding the level of support they feel they need and whether to involve their family in discussions. It should not be a prescriptive, nor imposed on people at such a difficult time of their lives. They believe it should be a ‘person-centred’ approach but supported by an identified lead professional.

100. The RCN Scotland stated in oral evidence that “We need to get person-centred care on the map, rather than just the typical care package. Every individual has different needs, and we can ascertain what they are only by holistic assessment at appropriate stages on the journey.”

101. A holistic approach to palliative care was an idea that the Committee also encountered during its visit to Ardgowan Hospice, Greenock. Clinical colleagues,
carers and service users all commented on the need for a holistic approach. They believed in treating the whole person and not just the nature of an illness.

102. NHS Education for Scotland also agreed that a holistic approach was needed:

People need different levels of palliative care throughout their illness and towards their death... We should focus on a holistic assessment of a person’s needs at a particular time... Rather than focus too much on one aspect, we need to help the system to join up so that people speak to each other.

103. The idea of a non-prescriptive model was, however, a recurring theme throughout the submissions. Many felt that there was no ‘best’ time or person to initiate discussions around palliative care and that each case was different. It was highlighted by Inverclyde in Partnership for Palliative Care that healthcare professionals should look for “cues” from the patient as to when they were ready to discuss the issue and that it would be welcome.

104. The majority of respondents believed that the discussion should be conducted face to face, with privacy, confidentiality and comfort provided for the patient and family so that they can take on board the issues discussed. Respondents thought the discussion should include anyone the patient wants to be involved and take place with someone who has good communication skills and knowledge of the patient. Macmillan Cancer Support also thought it was important that conversations take place before a crisis, so that patients have time to think through their wishes in advance.

105. Respondents also favoured open, honest and transparent conversations handled compassionately and sympathetically, with the needs of the individual patient in mind, involving the relevant healthcare professional, patient, family and carers. This ensures that all parties have an opportunity to discuss the options and what psychological or physical support is available for the patient.

106. It was felt that the pace of the conversation should be guided by the patient’s level of understanding of their diagnosis and that practitioners need to be trained in particular to listen and interpret, as well as providing information. Age Scotland also specifically mentioned people who are experiencing cognitive difficulties, and those supporting them, as they may find it difficult to have important conversations about options for palliative care. It was also highlighted that decisions at these discussions must be documented and shared.

107. The Association for Palliative Medicine generally felt that palliative care should be discussed whenever and wherever a need is identified – be it physical, psychological, social or spiritual. They felt that any healthcare professional should be able to initiate such a discussion if required and that diagnosis of a life-limiting condition should act as a trigger to put in place a plan to have a conversation, to be regularly reviewed, with the patient about palliative and end of life care. They also felt that a range of different events (e.g. frequent hospital admission,
admission to a care home, deterioration in health) should also prompt health and care professionals to consider the need for such a conversation.

108. The Committee also heard evidence that discussions on palliative and end of life care should not be a one off discussion. It should be returned to frequently as needs changed and during the trajectory of an illness. During the Committee’s visit to CHAS Rachel House parents discussed the different trajectories that their child’s illness took and how this meant there was a need to have ongoing discussions of their palliative care needs and wishes as required.

109. During oral evidence sessions the Committee heard that changes should happen as early as possible for the patient to benefit the most. The Association for Palliative Medicine of Great Britain and Ireland said:

> You may have heard about interesting recent studies of early referral to palliative care for people with lung cancer and a number of other diseases that found that patients not only had a better experience but lived longer.  

110. The RCN agreed with the need for the discussion to happen as early as possible, stating:

> We need to be able to have that conversation a bit earlier on the journey, to avoid people feeling that they are being passed from pillar to post... if we have those conversations sooner, it helps teams to put support in place a bit sooner. We must remember that along with the dying there are the living... We need more time to enable people to plan in a safe and effective way, so that they get the best outcome.

111. The Scottish Government noted that GPs are very well placed to have the conversation with people coming to the end of their life and with their families, as they are generally familiar with them. The Scottish Government also indicated that:

> One of the issues that we are trying to tackle and which I should draw to the committee’s attention is the willingness of individuals and families to have these conversations at the right time. That is in no sense a criticism of patients or families, but we need to provide a space in which they can have that conversation comfortably. Some people are more comfortable with that conversation than others are. It is up to us—it is our professional duty—to ensure that that conversation can be had. General practice is a critical part of helping us to do that.
112. The Committee understands that there is no perfect time or place for a discussion on palliative care to take place. However, the evidence the Committee heard was that the sooner that the discussion can take place (with someone confident and comfortable discussing palliative care) then the better the likely outcome for the patient. Early access to all forms of palliative care seems to have a positive impact on the quality of life for a patient.

113. The Committee believes that there is a need to equip all healthcare professions so that they are comfortable in initiating conversations around death and dying. This should not be an additional part of medical professional training but an integral part of delivering good healthcare.

114. Whilst the Committee highlights the role of education in addressing this later in the report, we recommend that the Framework identifies how this education might be mainstreamed into health and social care professional training.

115. More generally, the Committee questions whether the term ‘palliative care’ has become too closely linked to ‘end of life’ and ‘dying’ by the public and the medical profession more generally such that it can, in of itself, be a barrier to initiating the conversation. The Committee asks the Scottish Government to consider the role of other terminology in assisting with initiating conversations about palliative care.

Supportive and Palliative Care Indicators Tool

116. Professor Clark, within his report, discussed the use of the Supportive and Palliative Care Indicators Tool (SPICT)\(^\text{53}\). The SPICT has been in development since 2010 as a collaborative project between NHS Lothian and the University of Edinburgh Primary Palliative Care Research Group. The SPICT is a guide to identifying people, with one or more advanced conditions, who have deteriorating health and a risk of dying and who might benefit from the palliative care approach. The SPICT is now widely known, with international collaborators in Australia, North and South America and Europe. It has significant potential for use across care settings and has the ability to combine with other measures – such as palliative care registers and key information summaries.

117. Many of the written submissions to our call for evidence commented on the use of the SPICT. RCGPS\(^\text{54}\), Professor Scott A Murray\(^\text{55}\), NHS Lothian\(^\text{56}\), NHS Borders\(^\text{57}\) and NHS Tayside\(^\text{58}\) all comment that the SPICT has the potential for good within palliative care. It is expressed that the SPICT can help support the identification of patients irrespective of the underlying disease or illness and can be used to identify signs of poorer health that can easily be recognised by professionals.
118. During their evidence, RCN Scotland agreed that “SPICT was helpful in trying to identify those who may be expected to die within the next year.”

119. RCGPS felt that SPICT was a “useful starter for 10, but it does not really help us to get right down into the group that we need to be concerned about, whose ceilings of treatment and intervention we need to visit”.

120. The Committee believes that there is a need for the Scottish Government to set out in the Framework a tool to help earlier identification of those who require palliative care. The SPICT seems a good example of such a tool.

Recording Systems

Palliative Care Register

121. The design and implementation of the Emergency Care Summary (ECS) began in 2004, as a single, national record system that contains key details from GP records concerning demographic, medication and allergy information. The ECS copied items of data that already existed in GP practice systems and made it available to users who needed it as ‘read only’. It is fully rolled out across the NHS, and holds information on 5.5 million patients.

122. In 2010, the electronic palliative care summary (ePCS) was included within the ECS. It was designed to contain up-to-date information about palliative care patients, with both cancer and non-cancer diagnoses.

123. The Scottish Government advises that the ePCS improves communication between patients, carers and professionals at all stages of the patient journey by allowing data to be sent automatically and on a daily basis from GP systems to out of hours services.

124. In 2012, the Key Information System (KIS) became an extension of the ECS. This is designed to support patients with long term conditions or who have anticipatory care plans in place. A key aspect of KIS is that the clinician is required to work collaboratively with the patient to create the information that is included on the system. The ePCS and KIS were rolled out for those who needed it by 2014.

125. The RCGPS advised that the biggest issue for GPs in using the palliative care register is how to define that stage. They advised that the struggle in coming up with a working definition of what palliative care is, and who it is for, made it difficult to “work round the edges of that”. They also felt that if Palliative Care was clearly defined then it would become much easier for GPs to put patients on the palliative care register and increase its use.
126. Under the general Medical Services contract there is a Quality Outcome Framework indicator for GP practices to have in place a palliative care register. The Scottish Government advised that in 2008-09, 7,703 patients’ palliative care needs were recorded; that figure rose to 12,050 in 2013-14.63 They also noted that although there have been improvements against some of these measures, they have been modest. The data from GP practices on people with non-malignant diseases shows that, although there has been an increase in the number on the register, those numbers were not as high as the Scottish Government would expect. People are being identified, but not as many as the Scottish Government would like.64

127. The Committee notes that there are a number of forms (ECS, SPCS, KIS and anticipatory care plans – see the next section) to be completed by medical professionals, all of which can feed into the decision on whether palliative care is required.

128. The Committee believes that it would be helpful in simplifying access to palliative care if the Framework clearly identified how this information is to be accessed, shared and used to inform whether palliative care should be offered but also how each form relates to the other.

Anticipatory care plans

129. Anticipatory care planning is described as adopting a ‘thinking ahead’ philosophy of care that allows practitioners and their teams to work with people and those close to them to set and achieve common goals that will ensure the right thing is being done at the right time by the right person(s) with the right outcome. Advance care planning is the term most commonly referred to in end of life care, although it does incorporate the writing of wills or ‘Living Wills’ now known as advance directives or advance decisions which can be done by the well person early on in life to plan for what may happen at the end of life. Anticipatory care planning is more commonly applied to support those living with a long term condition to plan for an expected change in health or social status. It also incorporates health improvement and staying well. Completion of a common document called an anticipatory care plan is suggested for both long term conditions and in palliative care.65

What is an anticipatory care plan?

130. The Scottish Government describes anticipatory care plans (ACPs) as:

An Anticipatory Care Plan is a dynamic record that should be developed over time through an evolving conversation, collaborative interactions and shared decision making. It is a summary of Thinking Ahead discussions between the person, those close to them and the practitioner.
The ACP is a record of the preferred actions, interventions and responses that care providers should make following a clinical deterioration or a crisis in the person's care or support. It should be reviewed and updated as the condition or the personal circumstances change and different things take priority.

As the condition becomes more complex it may be helpful to discuss legal and practical issues as well as care and support preferences. As the needs and dependency of the person increase, it may become appropriate to explore end of life preferences within these conversations. The Anticipatory Care Plan will then include additional information about the person's:

- concerns and goals
- their understanding about their illness and prognosis
- wishes for end of life care, including preferred place of care, as well as their views about the degrees of interventions, treatments and cardiopulmonary resuscitation welcomed.

This type of information is currently recorded as a Palliative Care Summary. This summary is a specific component of an Anticipatory Care Plan for someone who has palliative or end of life care needs.

131. There was general agreement in submissions that Anticipatory Care Plans (ACPs) can play a valuable role in the delivery of palliative and end of life care.

132. North Ayrshire Health and Social Care Partnership suggested that ACPs should include patients’ physical, psychological, social and spiritual needs and wishes alongside their preferred place of care, their concerns and treatment goals. Angus Council explained that the ACP allows for person centred care, provides the individual with more control and choice and removes any ambiguity about these choices. For more complex patients involved in specialist palliative care, it may also involve clarifying the extent of treatment desired, including withdrawal, and provide a goal to work towards. NHS Ayrshire and Arran said that it was rare for patients to come into or go out of the acute settings with a formal ACP document. The necessary information is usually included within the KIS and/or within clinical notes. However, NHS Ayrshire and Arran request the GP (and encourage ward medics) to populate/update the KIS in terms of the desired place of care and death, resuscitation status, treatment withdrawal, patient goals, and relevant end of life anticipatory drugs in order to improve access to information out of hours.

133. Respondents felt that ACPs are good for initiating conversations with patients about palliative and end of life care and valuable for recording people’s wishes. Sharing this was felt to be a useful form of communication between health and social services and, in particular, between day time and out of hours (OOH) care.

134. RCN believes that “advance care planning is crucial to ensuring that patients are making active choices about their end of life care while they are still able. Analysis of work carried out in NHS Shetland has shown that patients with advanced care
plans who were seen out of hours were cared for according to their plan without introducing alternatives which may have resulted in an inappropriate admission to hospital. Such early intervention can reduce the over or under treatment of patients.”

135. During oral evidence, the Scottish Public Services Ombudsman noted that the cases that they see are ones in which there has not been an anticipatory care plan or discussions with family members. This includes where there has been conflict between what the patient would like to happen and what the family members would like to happen. This is usually as a result of those conversations not having taken place. Whilst the Ombudsman could not offer advice on ACPs they could note that not having one can cause problems.

136. A number of submissions said that ACPs should be completed as early as possible and not be left until the end of life care stage. Others suggested that ACPs are helpful in passing on clinical information to other agencies, including NHS 24, when GP’s are unable to be directly involved in care. However, it was considered that they were only effective if assessed and utilised by wider clinical and care teams. This can be problematic as IT systems are often not compatible and all staff involved in the patients care may not be able to access the ACP. For example ambulance crews may not have access to peoples wishes in terms of attempting resuscitation.

137. The Association for Palliative Care for Great Britain and Ireland spoke of the need to focus on the primary care record even if access is without “write rights”, having access to read the patient’s wishes on the system would alleviate a lot of problems. They also spoke of the need for a “real-time” system:

> When a call goes out, an ambulance crew should within three to five minutes be able to access, within the ambulance, a care record that says what a person is likely to be facing and, in particular, what they do or do not want to be done. That would make joint decision making and personalised care real.

138. Parents at CHAS Rachel House advised how CHAS had supported them in taking the fear out of the situation that they and their child are facing by encouraging discussion of their child’s ACP. The parents were agreed that this should be a “live” document that is updated to reflect changing family circumstances and the child’s health needs. They also agreed that access to the ACP should be available on different platforms so that services such as the Scottish Ambulance Service had access to it.

139. Submissions mentioned that individuals can and do change their minds when a crisis is looming, so there is a need for ACP flexibility and review. Having a ‘plan B’ was therefore thought to be essential. It was also agreed that planning for getting ill is less distressing for many people than ‘planning for dying’.
140. One potential solution to this was mentioned in some submissions by using the computerised electronic Palliative Care Summary (ePCS) and electronic Key Information Summary (eKIS) systems which are regularly updated from GP records. These may help improve the implementation and take-up of ACPs by storing easily identifiable information on them in one place.

141. RCGPS stated that the KIS is taking over from the ePCS and as it is attached to the ECS it gets uploaded out from general practitioner medical records along with the ECS. They advised that the KIS attaches a greater deal of information, having five separate subheadings, one of which is palliative care.

142. The Scottish Government noted that anticipatory care planning had to take into account the fact that the system could not be a ‘one size fits all’ system and that the conversation should be tailored and individual to each person. This would allow not only the condition of the person but also the preferences of the person living with it. They also stated that there was a need to take account of the views of relatives and unpaid carers.

143. Respondents discussed the limitations of ACPs as well. They said that ACPs tend to focus on the practical elements of caring for the individual’s complex medical needs without addressing the wider issues surrounding their social care needs. And while keeping the ACP up to date is essential, access to it can be fragmented, because if it is on the GP’s recording system, it is not available to others, including essential third sector nursing staff. As a result, a number of submissions suggested that the KIS should be made available throughout secondary care compared to the current limited access.

144. Marie Curie, in its written evidence, told how hospice consultants cannot add to the patients KIS as only general practitioners can currently do this. They also advised of system compatibility issues surrounding the use of Do Not Attempt Resuscitation (DNACPR) orders in end of life care. These conflicts within electronic systems, and how data is reorganised within these systems, can lead to healthcare professionals being unclear on patient wishes. They felt that there need to be mechanisms to consistently share information in a timely and accessible way, with an effective IT infrastructure to support it. They also believe there need to be systems in place to recognise when people need palliative care early in their pathway.

145. Inverclyde in Partnership for Palliative Care commented that:

> The key to better uptake is education and reinforcement of how an appropriately timed and communicated ACP can positively impact on a patient, their carer and family’s journey”.

146. They continued by saying that this requires ongoing audit, improvement science and clinical reflection. Another respondent suggested that better advertising of ACPs is needed with concerted efforts in the local media and within GP practices.
147. The Care Inspectorate told the Committee that there were encouraging signs of increased uptake within care homes. They advised that the number of older people in care homes who, at the point at which they died, had an ACP has increased from 38 per cent in 2012 to 63 per cent in 2015. The Care Inspectorate advised that this figure is lower for other groups, and that in 2014 only 27 per cent of ‘other adults’ in care homes had an ACP at time of death. It was explained that this could be for a number of reasons, for example, a resident may not be considered to be at or near end of life.

148. The Scottish Ambulance Service advised that there was a need to bring forward plans to provide anticipatory care planning across all disciplines, and embed palliative care processes into them.

149. The Scottish Government concludes that ePCS will help provide the opportunity to develop ACPs which may include:

- medical diagnoses as agreed between GP and patient
- patient and carer understanding of diagnosis and prognosis
- patient wishes on preferred place of care and DNACPR
- information on medication and equipment left in the patient's home 'just in case'.

150. The Scottish Government highlighted that anticipatory care planning was not a one-off conversation, stating that—

“there should be a continuing and live process throughout the patient-clinician interaction. A patient or a person can develop an anticipatory care plan in discussion with their clinician, but that needs to be revisited over time. Care planning is an active element of the care. It involves checking that the plan is still current and that it is consistent with an individual’s condition.”

151. The Committee welcomes the Care Inspectorate’s findings that there have been improvements in the uptake of anticipatory care plans in care homes. We consider that further steps should be taken to further encourage and support their use. The Committee considers that there is a role for the Scottish Government in further promoting the use of ACPs and encouraging the uptake across other sectors.

152. The Committee notes however that an increase in the uptake of ACPs has to also equate to an increase in them being used. The Committee believes that the Scottish Government should include in its Framework some mechanism to monitor how well ACPs are implemented.
153. The Committee believes that anticipatory care plans must be accessible to different health professionals, as appropriate, whilst still ensuring that patient confidentiality is not breached. The Committee therefore recommends the Scottish Government reviews who may access ACPs to ensure that “joined-up” access is available across the range of health practitioners who may require to support patients with ACPs.

Access to palliative care

154. In his report, Professor Clark reported that, by using projections based on English data, an estimated 10,600 people per year in Scotland would benefit from palliative care but are currently not receiving it. It was also found that access to palliative care varies greatly depending on a person’s condition, place of residence and care setting. Evidence showed that lower levels of awareness of hospice and palliative care and language differences amongst minority groups may limit their use of services. 

155. The inquiry responses also indicated that access to palliative care services across Scotland was variable, particularly between the type and level of care available. Frail older people with multi-morbidities and dementia, and marginalised groups (people experiencing homelessness, prisoners, people with learning disabilities etc.) were identified as having worse access. Inequalities in access both geographically, and for some ethnic groups, were also a concern.

156. Particular groups of patients were highlighted as being less likely to receive general palliative care than those with cancer. For example, people with terminal degenerative conditions such as dementia, chronic obstructive pulmonary disease (COPD) or heart failure, or conditions such as motor neurone disease (MND) or multiple sclerosis (MS). Some of the challenges identified around this included the reluctance of patients with organ failure to accept the palliative nature of the disease, the unpredictable trajectory of illness, frailty, and the confidence of medical and nursing staff to have conversations around palliative care needs.

Pathways and models

157. There has been much media coverage around the failure of the Liverpool Care Pathway. The lack of involvement of patients or relatives in decisions regarding end of life care was highlighted to the Committee as one of the major flaws of the Liverpool Care Pathway.

158. With the removal of the Liverpool Care Pathway, national guidance was set out by the Scottish Government in December 2014 and it is supporting people to share what works well through their national infrastructure.
159. Many respondents commented on the inconsistent access to palliative care. Various submissions discussed pathways and models for improving equity of provision for palliative care. Some of the suggestions for improvement are outlined below:

- Palliative care needs to be integrated into clinical pathways for all disease groups to enable prompt timely involvement, the identification of best interventions and delivery models for non-cancer patients.
- Developing a palliative care pathway that is fully operational and adequately resourced.
- Implement key sequence of identification first, then assessment and care planning and symptom control in all settings.
- There should be early referral to palliative care services. Macmillan Cancer support indicated that this leads to better quality of life, reduced symptom burden, less exhaustive care and lower costs.
- Develop more rapidly responsive models of support in the community to avoid unnecessary/undesired hospital admission and to facilitate discharge.
- Testing of new models/ways of working to support earlier identification and engagement.

160. During oral evidence, the Scottish Government advised that since ceasing the use of the Liverpool Care Pathway it has convened a group of clinicians to provide recommendations on a new framework. The Scottish Government received advice that what was needed for care in the final days and hours of life was national guidance that focused on four principles:

- informing people and communicating with them in a timely and sensitive way at the end of life
- ensuring that significant decisions involve all aspects of the care team
- ensuring that the focus is on psychological, social and spiritual care as well as physical care
- ensuring that the wellbeing of relatives and carers is factored into the care planning.

161. The Scottish Government advised that it took the decision not to introduce a new national pathway, because one thing that it learned from the Liverpool care pathway review was that teams need to be able to tailor their local care processes to local systems and care facilities. The Scottish Government guidance provides a framework for local boards and partner organisations to develop their own approaches, and they have created a national mechanism for organisations to share their particular resources.
162. The Committee supports the Scottish Government decision to cease use of the Liverpool Care Pathway and believes that there are advantages in tailoring care delivery to local circumstances. However, the Committee has some concerns as to how consistency of care can be provided in those circumstances.

163. The Committee recommends that the Scottish Government Framework addresses how the Scottish Government will ensure consistency in access to and the provision of palliative care across Scotland.

Malignant versus non-malignant

164. Palliative care treatment should be available to all who are suffering from a life-limiting illness. Evidence, however, seems to suggest that access for cancer patients is much better than for people with other life-threatening illnesses.

165. RCGPS stated that:

…they are still heavily weighted toward people with cancer diagnosis. I would argue that that is because people with a cancer diagnosis are far more likely to be willing to be considered as palliative.77

166. Strathcarron Hospice advised that referrals for non-malignant diseases have increased by 20 per cent over the last 5 years and that primary care staff need to be more aware that they can refer non-malignant patients for palliative care.78

167. Sue Ryder commented that

People with non-cancer conditions, including neurological conditions, are less likely to have access to palliative care. This is because firstly, these conditions often have a less predictable disease trajectory than cancer which makes prognosis less certain and secondly, these conditions are less prevalent in the population so health professionals are less experienced in these conditions and find diagnosis more difficult as a result. This means diagnosis is often late, if it happens at all, and people with neurological and some other non-cancer conditions are much less likely to receive the level of support they would have been able to have, had they been diagnosed earlier. In addition, prognostic indicators and an understanding of palliative care are generally better understood by oncologists than other specialists.79

168. RCGPS also commented that there was an issue with people with non-malignant conditions accepting that they were at the palliative phase. They stated that “I looked after someone with motor neurone disease who was incredibly reluctant to accept that death was inevitable.”80 They went on to explain that sometimes it was
their role, as health professionals, to try to explore with people the fact that they are now at a stage where they are considering the imminence of their death.

169. During the oral evidence session on 29 September 2015, Alzheimer Scotland noted that identifying the end-of-life phase for people with dementia was very difficult, particularly when someone is dying from dementia, rather than with dementia. Due to the variable trajectory of dementia it is very difficult to predict how many dementia sufferers in Scotland will be coming to the end of their life.

170. The SPPC also agreed that access was easier for people with cancer diagnosis, stating “People with cancer are much more likely to get the palliative care support they need than people with non-malignant conditions (including frail older people with multi-morbidities and dementia), and this applies both to specialist palliative care and generalist palliative care support”. 81

171. South Lanarkshire Council and Aberdeen Health and Social Care Partnership both commented that the condition a person is diagnosed with can have a huge effect on the palliative care that is received. Aberdeen Health and Social Care Partnership commented that “sometimes practices find it harder to decide to put a patient with heart failure/COPD on palliative care register because although they might die within next 12 months, they might also live for much longer”. 82 South Lanarkshire Council noted that “Substantial funding has been committed to supporting people with cancer and their carers across Lanarkshire but in other areas of palliative care (e.g. Dementia, COPD, Motor Neurone etc.) arguably funding commitments are much less”. 83

172. Macmillan Cancer Support felt that assumptions are made that all cancer patients receive good palliative and end of life care already. However, they stated that between one quarter and one third of cancer patients were not identified as having palliative care needs. For cancer patients, the final phase of illness (from the point where curative treatment is no longer deemed appropriate, or is not chosen) can range from several years to only days. Those diagnosed in the later stages of their disease are more likely to have unmet palliative care needs. It is estimated that more than 2 in 5 people in Scotland will develop cancer during their lifetime and as more people live longer with cancer, their need for palliative care will increase to enable them to live well with their disease.

173. The Committee notes Macmillan Cancer Support’s comments that there is a perception that cancer patients receive better palliative care.

174. The Committee is pleased to hear that registration of non-malignant illnesses on the palliative care register is increasing. However, despite this increase, there still remains an issue with access to palliative care for people with non-malignant diseases.
175. The Committee believes that palliative care should be provided on a ‘need not diagnosis’ basis. As such the Committee reiterates its recommendation that services must be tailored to the need of the individual and be ‘person-centred’.

176. The Committee believes that there should be a right to palliative care, and that any barriers to access, whether diagnostic or otherwise, must be removed. The Committee asks that the strategic framework sets out how palliative care can be accessed at point of need.

177. The Committee also requests that the Framework sets out how the Scottish Government will assess at a national level whether people are able to access palliative care when needed and how it will identify any barriers to access.

Marginalised groups

178. Marginalised groups (people experiencing homelessness, prisoners, people with learning disabilities etc.) were identified as having worse access to palliative care. Inequalities in access both geographically, and for some ethnic groups, were also highlighted as a concern.

179. East Dunbartonshire Council highlighted in their evidence that there are hard to reach groups such as substance misusers and homeless people who do not engage with services and then there are people in prison who need special attention. East Dunbartonshire Council particularly wanted to highlight the issues affecting people with a learning difficulties—

Increasingly, people with a learning disability are surviving well into adulthood and into old age, and many of them either are being cared for in supported accommodation units or are known to social work and have particular needs…We know that, for a number of reasons that I will not go into, people with a learning disability do not do well in hospital, but care homes might not be geared up to meet their needs. There are medical aspects such as the difficulty of assessing the pain that somebody with a learning disability is experiencing. They might also lack a sense of time so it is difficult to know the best time to try to engage with them and talk about end of life. They might immediately think that it is imminent.84

180. Inverclyde in Partnership for Palliative Care noted that a priority had to be to “Improve access to psychological services and care for marginalised groups such as people experiencing homelessness.”85
181. The Committee believes that there should be equal access to palliative care and requests that the Framework identifies how the Scottish Government will monitor whether access is improving for marginalised groups.

Children and young adults

182. The Committee understands that access to palliative care for children differs from that for adults in that there are different types of need and conditions and that often the trajectory of illness varies significantly from that of adults.

183. CHAS stated that “For children, their condition’s timespan might extend into years, so palliative care for children is often around for years”.

184. Discussions around palliative and end of life care are difficult in any situation but particularly around the health of children. Part of the access issue seems to be that the benefits and positive impacts that palliative care can bring to a child with a life-shortening condition are not as well-known as they might be to families, and particularly to professionals.

185. During their visit to CHAS Rachel House the Committee heard from two parents of children who benefited from access to the hospice. They spoke of very different experiences of palliative care and accessing support. The difference in the support that they received came down to differing local authority approaches.

186. The submission from the Royal College of Paediatrics and Child Health stated that:

> Palliative care for children is different from adult palliative care and appropriate services for children and young people need to be available in all areas, in an appropriate location, whenever they need it, 24 hours a day, seven days a week. This must include specialist paediatric palliative medicine consultants and adequate specialist paediatric palliative care nursing provision so that every family of child with a life limiting condition has access to one. There needs to be consistent community children’s nursing and support for children’s hospices, both of which provide essential respite. 86

187. The Committee was also made aware of issues surrounding the transition from child to adult services. The Royal College of Paediatrics and Child Health commented that:

> The number of 16 to 19 year olds with life-limiting and life-threatening conditions has nearly doubled across the UK in the last decade. Managing the transfer of their health and other care needs to adult services is challenging and adult services often struggle to provide appropriate services for young people with life-limiting conditions. Arrangements for
transition should accord with best practice and be respectful—insofar as possible—of the wishes, preferences, beliefs and values of those concerned”. 87

188. The Committee acknowledges the importance of recognising the difference between child and adult palliative care and asks that the Scottish Government ensures that this is reflected in its Framework.

Petition PE01499 – Respite services for younger disabled adults with life limiting conditions

189. One area where the Committee received evidence on the impact of those with life-limiting conditions living into adult was with regards to the provision of respite services for young adults.

190. Petition PE01499 - Creating Suitable Respite Services for Younger Disabled Adults with Life-limiting Conditions 88 was referred to the Health and Sport Committee on 18 February 2014. This petition calls on the Scottish Parliament to help create suitable respite facilities to support younger disabled adults aged between 21 and 45 with life shortening conditions.

191. The petition details how young adults were previously able to access the two CHAS hospices in Scotland for respite care. However, on 8 May 2013, CHAS announced that it was withdrawing its services for those aged over 21. The petitioner explained that this will result in their being no tailored respite services for those over 21. The petitioner goes on to state that:

> Currently, all adult hospice services are set up largely to cater for much older adults suffering from cancer and other terminal illnesses, and some of these hospices often don’t provide respite breaks, just end-of-life care. They are just as unsuitable a place for our age group to go to as children’s respite services are. The petition calls on the Scottish Government to address this gap in provision.

192. On 18 June 2014 Alex Neil, then Cabinet Secretary for Health and Wellbeing responded to the petition advising that this was an area of ongoing need and outlining the steps that the Scottish Government was taking in relation to the gathering of evidence in three specific areas:

- Establishing Scottish Data to determine the scale of the issue;
- Mapping the breadth, capacity and quality of existing services; and
- Analysing economic evidence relating to running a bespoke service.
193. On 3 August 2015 the Cabinet Secretary for Health, Wellbeing and Sport wrote to the Convener providing a further update on the Scottish Government’s progress with the petition. The update advises that the Scottish Government has:

- granted funding to CHAS through the Managed Service Network for Children and Young People with Cancer to undertake research.
- met with the Muscular Dystrophy Campaign and various other stakeholders to look at what more they could do to move this issue to the next stage. The meeting agreed the short term focus of actions should be the needs of the 41 young adults over the age of 21 currently using CHAS services. The medium to long term focus is to generate a range of options that could meet a wider range of needs.

194. The Cabinet Secretary also advises that the Social Care (Self-directed Support) (Scotland) Act 2013 also contributes to the provision of respite care and allows for people to have greater flexibility, choice and control over the support services they receive. The letter goes on to detail that the Public Bodies (Joint Working) (Scotland) Act 2014 puts in place arrangements for integrated health and social care. The aim of this is to improve outcomes for patients, service users, carers and their families.

195. CHAS commented on this issue and agreed that respite was incredibly important. CHAS are working with every adult hospice in Scotland so that young people can have a choice about where they want to go for respite care. This included working with Marie Curie in Glasgow and arranging focus groups to help them understand what could be provided for young people. CHAS is working with Leuchie House in North Berwick to test respite breaks there.

196. The Committee welcomes the joint work that the Scottish Government and CHAS are currently undertaking to look at how respite services for young adults can be improved and increased.

197. The Committee is also pleased to hear of the pilots between CHAS and Marie Curie, Glasgow and also Leuchie House in North Berwick which will hopefully result in a range of additional respite options within Scotland.

198. The Committee notes that this is an area of growing need and therefore seeks confirmation from the Scottish Government of the timescales for when it would expect to establish a model of care for young adults that can be replicated across a wide range of respite settings.

**Achieving consistency of approach**

199. Consistency of approach to supporting those with palliative care needs has been highlighted to the Committee in nearly all of the evidence provided. With a wide range of ideas on how to tackle this issue presented to members.
200. Scottish Care spoke of how when a person is diagnosed with dementia they are provided with a one-year post-diagnostic support. The purpose of this support was to have a co-ordinating worker, whose role was to help the family and the individual come to terms with the diagnosis and to co-ordinate the support around the patient. Scottish Care believe that there could be scope for something similar in palliative care and that “having a key worker – a co-ordinating presence – involved in somebody’s care could well be a positive model to consider”.  

201. Dr David Carroll, NHS Grampian agreed and said “I am keen for someone to be in control or to be organising a lot of the care. Palliative care in a community setting is becoming multistranded and we do not want the strands to be tangled up randomly; instead we want them to be pulled together in a cohesive way in order to maximise the quality of care that an individual gets”.  

202. RCN Scotland also commented on the need for there to be a single point where patients and their families can access the variety of services they will require in a joined up and holistic manner. They felt that those services could include community nursing, Allied Health Professionals, GPs, social work and third sector services, among others. RCN believe that having a named professional could be hugely beneficial in coordinating care and being the link for families. However they conclude that no individual professional can be available 24/7, 365 days a year. Local services need to ensure their systems take this into account so that patients and families are never left wondering who to call if they need help.  

203. North Ayrshire Health and Social Care Partnership note that the way to ensure equity of access is “Through the development of high quality, locally delivered end of life care”. They believe that this can be achieved by working with hospice and other partners to design and deliver end of life care that builds capacity within local health and social care professionals while ensuring rapid access to specialist advice and support. They believe that a key element of this will be building specialist capacity in care at home, district nurse and GP teams to support individuals and their families in the community and to develop specialist inpatient facilities outwith community hospitals.  

204. Pancreatic Cancer UK believes that all GPs and NHS trusts should have access to community palliative services, either electronically or in paper form. Clinicians in primary and secondary care should be given regular communication from palliative services on how to refer patients to their services. GPs should be immediately informed when a palliative care patient is discharged from hospital. The need for palliative care should be a priority on the records of all patients with a cancer diagnosis, serving as a reminder to healthcare professionals.  

205. The Committee acknowledges that there is the need for access to palliative care to be more consistent across all conditions, ages and locations. The Committee asks the Scottish Government to set out in its Framework its approach to ensuring consistency of access.
206. The Committee recommends that there should be an easily accessible source of information for people once they have been diagnosed which advises what palliative care services are available and where. We recommend that the Framework addresses this issue.

Where is palliative care provided?

207. Palliative care can be provided in a range of different settings. From a patient’s own home, care homes, hospitals, hospices, respite care and out-of-hours services.

Home setting

208. Much palliative care is provided in the home. This can be provided by health care professionals, family or carers. The Scottish Government National Performance Indicator measures how many people spend the last six months of life at home or in a community setting. However this measure has been questioned for not taking into account the quality of care patients received or what the patient’s preference was for where their care was provided.

209. The RCGPS noted that:

“As stated in the current RCGP Scotland Policy Document on End of Life Care, the provision of end of life care is a core component of the work of a general practitioner. Although the majority of deaths still occur in NHS hospitals, 90% of a patient's last six months of life are spent at home or in a community setting. Primary care teams, in which District nurses play a key part, have a central role in coordinating and delivering the care that these patients require and contribute very considerably to end of life care.”

210. Scottish Care stated that providers of home care were not choosing to provide 15 minutes of care when visiting the homes of service users and that, most of them were opposed to that. However, those who commission the care (usually the public body) penalise independent organisations that exceeded the 15 minute time limit for each visit.

211. COSLA advised that:

“It is not helpful to characterise this as a problem that is present in only one part of the system and not in others. The point is the amount of time that is required to deliver the outcomes that we want. We are trying to move towards outcome-based commissioning. That said it must take place within a resource envelope that is becoming even tighter. The pressure that social work budgets have been under for a number of years is simply not sustainable. Several times in this meeting we have talked about the need
for a wider debate around that – it is the elephant in the room. We are starting to see the impact of budgetary pressure.

212. The Committee has recently completed its Stage 1 report on the Carers (Scotland) Bill. Carers have been highlighted throughout this inquiry as being a major provider of palliative care to people, sometimes without even realising so.

213. Marie Curie noted that “many of those carers do not get the support that they need...The support that we give carers is really important in ensuring that the good care that a person is getting at home continues”. 94

214. The Committee is concerned to hear about the impact of care from home visits being limited to 15 minutes. The Committee recommends that the Scottish Government investigates what can be done to strengthen the home care system to ensure that quality palliative care is being provided in this setting.

Care homes

215. The Committee heard that care homes are delivering palliative care every day, but may not even recognise that they are.

216. RCGPS highlighted that “care home staff...who supply lots of palliative care. They do not even know that they are doing it and they often do it extremely well, unrecognised and with a skeleton staff...That is really good-quality palliative care and they are not given credit for it”. 95

217. COSLA noted that “we, as a society, do not value social care in the same way as we value NHS care. We are not willing to pay decent wages for social care, which causes problems with recruitment and retention in the workforce. Against that backdrop, it is difficult to upskill staff and ask them to take on more responsibilities that may be outwith their traditional professional boundaries”. 96

218. The Committee heard much about the need for social care to be regarded as a better career option for many and that there is a need to reward and value social care roles more strongly. The committee was informed that in Sweden staff that work in children’s homes are the most qualified and best remunerated care workers. In a sense Sweden has turned the system upside down and people there cannot understand why in the UK people who work in residential settings or in social care are generally at the less well paid end of the workforce.

219. RCGPS noted a case where one of their patients with MND could not be guaranteed a night carer every night of the week. They stated that we need a lot more home care professionals and that this is a macroeconomic issue – “they are working with the most vulnerable and needy people in society, and we pay them less than they would get if they were stacking shelves in Tesco, that does not work for me”. 97
220. During the Conveners Group evidence session with the First Minister the Convener of the Health and Sport Committee raised the issue of wage levels for social care workers. The First Minister was advised that the Health and Sport Committee had recommended that social care staff should receive the ‘living wage’. The First Minister responded that:

> the Cabinet Secretary for Health, Wellbeing and Sport, along with the Convention of Scottish Local Authorities and individual local authorities, is looking very hard at how we extend the principle and practice of the living wage into the social care workforce. There are two main parts of the social care workforce: those who work in care homes, and those who provide care in people’s own homes.”

221. The First Minister wrote to the Committee on 24 October 2015 providing further details on the ‘living wage’. The letter noted:

- all directly employed staff, within NHS Scotland, receive at least the Living Wage;
- Scottish Government is working with health boards to see how they could extend the living wage to contracted staff;
- the Scottish Government is working to promote the social care sector through opportunities such as addressing low pay in the sector;
- the Scottish Government provided funding of £10m per year to assist with improving the quality of care in care homes. Within this approach, a key focus is to tackle the issues of recruitment and retention in the sector;
- the Scottish Government will continue working with partners to further progress fair work practices.

222. The issue of social care staff receiving the ‘living wage’ was previously raised by the Committee in its inquiry into the Regulation of Care for Older People. The Committee heard from Scottish Care that turnover in the sector was too high and that:

> We have to get the skills mix right, which requires investment in training. We must also make it an attractive and rewarding occupational sector for people to come into. If we do not, we will, in the not-too-distant future, hit a crisis of not having enough people with the right skills mix, as well as the right values and attitudes, to deliver the care that we are going to need.”

223. In its inquiry report the Committee recommended that:

- The Committee considers that for many years the social care workforce has been undervalued – as reflected in wage levels, terms and conditions and limited investment in training and development. Looking to the future, the
Committee believes that in order to ensure that care services are of the highest quality, the sector must be seen as an attractive occupation for people with a range of skills. Current fiscal austerity measures should not be seen as an excuse to drive down wage levels. The Committee considers that employers in the social care sector should aim to pay all staff at least the “Living Wage”.¹⁰¹

**Hospitals and hospices**

224. The Committee heard evidence on the role of hospitals in relation to palliative and end of life care. Much specialist palliative care is provided in an acute setting but there may be issues within hospitals when it comes to switching from curative to palliative care.

225. The SPPC noted that:

> Although there is some very good end-of-life care in hospitals, our hospitals largely come from a model of cure, and we need to try to make them places where it is possible for good holistic care to be provided in circumstances where cure is not possible. That is a challenge in busy acute hospitals. There are good examples of care, but we need a bit of a culture shift around that and to recognise that, as I said, a big part of what Scotland’s acute hospitals do is to provide care for people in their last year of life.”¹⁰²

226. Scottish Care noted their concern about the “medicalisation of death”. They commented that “It is no longer a natural process; it is now something akin to an illness. That seems to me to be a misfortune.”¹⁰³

227. In oral evidence the Healthcare Improvement Scotland advised that they do not look specifically at palliative care through their current inspection programmes. They stated “In the inspection programme for the care of older people in acute hospitals, for example, we touch on palliative and end-of-life care through the different themes that we look at. In our strategic inspections of adult services, which we do with the Care Inspectorate, we look at services in the wider sense. Some of the people whom we speak to are at the end of their life, but some are not.”¹⁰⁴

228. The Committee visited CHAS, Rachel House and Ardgowan Hospice to speak with hospice staff and service users. During the visits members of the Committee witnessed excellent care being provided within modern facilities. During the visit to CHAS, Rachel House the Committee was able to see that the hospice did not just provide care to the patient but also to the whole family. For example having family rooms at the hospice allows the whole family to come stay and lets siblings enjoy the facilities and parents have respite.

229. RCGPS commented that “My experience of patients who have had specialist palliative input in one of the local hospices, for example, is that it is truly tremendous. It is fantastic”.¹⁰⁵
230. One of the issues highlighted to the Committee surrounding hospices is around funding. The Committee understands that statutory funding of children’s hospice services in Scotland is currently guided by the Scottish Government Chief Executive Letters (CEL) 12 (2012) which states that NHS Boards and local authorities will jointly meet 25 per cent of the mutually agreed running costs. Within the same CEL, funding for independent adult hospices is at 50 per cent of mutually agreed costs.

231. In its written submission CHAS explained that the NHS board and local authorities will jointly meet 25 per cent of its funding. The Committee heard that only around 13.5 per cent of the total cost of NHS funding for CHAS is administered through NHS Tayside and that CHAS is predominantly funded through the generosity of supporters across Scotland and beyond.106

232. CHAS advised that—

...there is what I would call an anomaly between the funding of children’s hospice services and the funding of adult hospice services. My ambition in my early discussions with the Scottish Government is to achieve 50 per cent funding of agreed hospice costs, which I am sure that the committee will support.107

233. The Committee raised concerns regarding funding in its report into NHS board budgets 2015-16. The Committee received evidence from NHS Tayside that in 2013-14 out of overall care costs for CHAS of £9 million, the NHS provided a total of £655,000, 7.2 per cent of CHAS care costs.108

234. The Scottish Government explained in correspondence that there was limited data about the number of children and young people requiring palliative and end of life care which meant that it was difficult for CHAS to provide evidence of the need for their services and the specialist nature of what they provide compared to palliative care provided by health boards.109

235. Overall, the views received on hospice care are all very positive. During the Committee visit to Ardgowan Hospice all the service users spoke very highly of the different services available. They also spoke of a misunderstanding among many of them as to what the role of a hospice actually was. Prior to attending they all believed that a hospice was
somewhere that you went to die. They did not realise that they could attend for holistic therapies, support groups and use it as a transport service for attending hospital treatments. There needs to be a better understanding that attending a hospice does not mean that you are giving up on curative treatment.

236. This is especially important with children’s hospices. CHAS noted that:

> Referral to a palliative care service for a child with a life-shortening condition does not mean the end of curative treatment. It simply means that that child and family have access to a life-enriching experience and to professionals who are perhaps better able to manage symptoms, who have the time and ability to sit down with the family and understands what matters most to them and who can work with the entire team around the child to make that happen. Everyone needs to have an awareness”.

237. The Committee also heard that there were differences in referral routes to hospice care. Service users of both CHAS Rachel House and Ardgowan Hospice spoke of their varying routes. Some were referred via their consultant whilst others only found out about them through routes such as the patient transport service.

238. The Care Inspectorate advised that they were engaging in joint inspections with Healthcare Improvement Scotland. The Care Inspectorate stated that they had carried out four joint inspections as part of a programme of Scotland-wide inspection. They scrutinised services to ensure that they were working well together to deliver good care for adults and older people in particular. They have a specific quality indicator as part of these inspections on prevention, early identification and intervention at the right time, and that allows them to look at the way in which palliative care is planned and delivered across healthcare and social care.

239. The Committee recognises the important work that CHAS and other hospices carry out and the support that they offer families at one of the most difficult times of their lives.

240. The Committee is concerned that boards are not currently delivering the agreed 12.5 per cent of hospice running costs agreed for CHAS due to not all CHAS running costs being included in the commissioning discussions with NHS boards.

241. The Committee seeks assurances from the Scottish Government that base-line funding, such as the 12.5 per cent indicated by CHAS, will be met for hospices going forward.
242. The Committee believes that there must be more consistent and long term funding arrangements in place for hospices. The Committee notes the comments made by CHAS regarding revisiting the baseline for funding CHAS hospices with the Scottish Government. The Committee asks the Scottish Government for further information regarding timescales for this negotiation.

243. The Committee also suggests that there needs to be more consistency in referral routes into hospices and if this was achieved there may be a more consistent level of access to these services for all. The Committee asks the Scottish Government to provide for clear guidance on the referral routes to hospice services in the Framework.

244. The Committee believes that there is merit in Healthcare Improvement Scotland being given a specific role to assess the quality of palliative care and recommends an increased emphasis on this area in their inspections.

Hospice at home services

245. The Committee heard about hospice at home care services on its visits to both CHAS Rachel House and Ardgowan Hospice. CHAS advised that they provide the CHAS at Home service, which aims to augment care at home and in hospitals for babies, children and young people with palliative care needs and they also contribute to CARE24 throughout the Lothians which, in conjunction with NHS Lothian, provides a 24 hour end of life service. NHS Lothian provides cover during the day with CHAS picking up the service at night. This service is used by people who have highlighted in their ACP that they wish to die at home. CHAS advised that there was frustration that this service was not provided over the whole country.

246. CHAS advised that “a family can be supported by a package of care and the CHAS at home team, so that they have access to specialist expertise as and when they need it.”

247. Ardgowan Hospice advised that they provide an outreach service Monday to Friday between 9am and 5pm. The service is carried out by specialist nurses who work alongside district nurses, Ardgowan are currently looking to extend this service to cover 7 days a week as they understand that health issues do not always happen during office hours.

248. Strathcarron Hospice highlighted hospice at home services as being one which needs to be developed as a priority for improving palliative care services. This would help support people in their own homes at end of life and provide rapid response to prevent admissions.
249. NHS Forth Valley noted that where ‘Hospice at Home’ and ‘Marie Curie’ services are available for people dying in the community, they are well received. However they were aware that it can be difficult to put these in place at short notice and the hours provided are sometimes less than is required.\textsuperscript{114}

\textbf{Out-of-hours care}

250. Between 2007 and 2011, half of all cancer deaths in Scotland occurred outside hospital according to Macmillan Cancer Support. This was felt to demonstrate a need for a comprehensive out of hours service with an understanding of specialist palliative care provision, planned respite care and care at home. Hospital specialist palliative care teams are usually available weekdays from 8am-5pm, alongside 24 hour telephone advice for professionals from community and hospital teams providing out of hours care across Scotland. This is usually provided by consultants but the Association for Palliative Medicine reported that it is challenging to sustain in areas where the consultant is working single-handed.

251. An outpatient service is offered for primary and secondary care referral by NHS Grampian. Face-to-face specialist palliative care assessment is not available seven days a week in most areas of Scotland and this was reported to be due to too few specialist staff being available. NHS Forth Valley highlighted that cover for community hospitals was also significantly less than for the acute hospitals and that access to specialist palliative care nursing is unavailable in hospital at the weekends.

252. NHS Grampian noted that “As we discuss workforce, skill mix and education, we must always be mindful of the fact that 70 per cent of the week is now deemed out of hours, and therefore we also require a workforce out of hours that has the same qualities and skill mix as the in-hours workforce. Unfortunately, illness is not a respecter of Monday to Friday, 9 to 5. Problems, such as deteriorations and acute symptoms, are statistically more likely to happen out of hours than they are in hours.”\textsuperscript{115}

253. Carole McGregor wrote:

…what haunts me most are the memories of that weekend, the fear and panic, the sense of abandonment and the utter desperation of our situation …people close to death should not be denied appropriate care simply because it happens to be a weekend”.\textsuperscript{116}

254. Jan Walker reported that her family was left to administer a controlled morphine drug up to two hours every day with no practical guidance and advice and asked for recognition that families cannot always provide practical care and support 24 hours a day.\textsuperscript{117}

255. Respondents agreed that people need a dedicated and immediately available 24/7 service providing access to planned respite, expert practical advice, emotional support and coordination for dying people and their families. This was desired
across all settings regardless of weekends, public holidays or geographical location.

256. The Scottish Government advised that Professor Sir Lewis Ritchie is currently leading a national review of primary care out-of-hours services and that one of the review’s task groups, which is chaired by the medical director of NHS Tayside and co-chaired by the RCN’s associate director for Scotland, will explore a range of groups that have been identified as vulnerable, including those with palliative care needs. Sir Lewis has met the Scottish Government’s palliative care policy team and attended the meeting of the Cross-Party Group on Palliative Care 15 March 2015.118

257. The Scottish Government advised that it has been examining the work that is done by hospices to provide advice out of hours and to link with colleagues in hospitals and other services where there is a changing situation. It has also been looking at the learning from the work on hospice at home. It believe that this approach will offer greater flexibility to change arrangements, deploy resource and allow people either to go home or to allow a plan for a change in the care setting. They are currently looking at where that is working in Scotland, working out why and trying to spread that learning and design it into the future system.119

258. The Committee is concerned to hear that support and help is not always available to families when they need it the most. The Committee believes that it is imperative that this is addressed and 24/7 access is available to those who require it.

259. The Committee is however, encouraged to hear that the Scottish Government is working to improve out-of-hours services and requests that the Scottish Government, as part of its national review of primary care out-of-hours services, identifies ways to improve out-of-hours palliative care services.

260. The Committee believes that if more people wish to die at home, as their preference, then either more hospice at home services are required or there has to be a much more coordinated approach between services. We will look to the Framework to address this issue.

Transitions between services

261. Many of the submissions received by the Committee spoke of the need for better transitioning between services for patients and the need for a “joined-up service”. RCN support the idea that there must be a single point where patients and their families can access the variety of services they will require in a joined up and holistic manner.
262. The Committee was advised that there may be inequality of access to palliative care depending on geographical location. Different levels of palliative care are available in different areas, depending on the health board or the local authority. The Committee heard that there can be issues around access in rural areas but on the other hand rural areas can have a continuity and cohesiveness.

263. Macmillan Cancer felt that “Collaboration between health and social care staff in managing the transition between care settings can be patchy e.g. ensuring the right equipment and medications are in place”.

264. During our visit to CHAS Rachel House the Committee heard of instances where parents whose child had complex-care needs were discharged without receiving appropriate guidance on how to use medical equipment that was provided for their child.

265. Whilst speaking with service users at Ardgowan Hospice the Committee heard that there need to be a more “joined-up” approach to services as they could currently go from GP to a Consultant to operation/treatment and then back to the GP with each not knowing what had gone before. There was also a general feeling that once they had completed their treatment there was a lack of assistance. There was no signposting to hospice care which provided a service that they all found beneficial.

266. The RCN felt that the implementation of health and social care integration should bring about a more seamless transition between services for those moving between medical care to palliative care and ensure individuals and their families experience a good death. They also noted that particularly in health, an enabler to this type of joined up care is a managed clinical network and that these networks of linked groups of health professionals and organisations from primary, secondary and tertiary care, work in a co-ordinated manner, unconstrained by existing professional and Health Board boundaries, ensuring equitable provision of high quality clinically effective services throughout Scotland.

267. Staff at CHAS Rachel House advised of the positive steps taken since the introduction of Diana Children’s Nurses. Diana Nurses are funded by the Scottish Government and aim to ensure parents and children with life-threatening or severely disabling conditions are given the support they need at home. They advised that since then regular discharge meetings have been taking place during which the Diana Nurse and the specialist will discuss the patients palliative care needs and the access to them.

**Integrated Joint Boards**

268. Integration authorities will be responsible for planning and delivering a wide range of health and social care services, and will be accountable for delivering the national health and wellbeing outcomes. Each integration authority will be required to publish an annual performance report, which will set out how they are improving the national health and wellbeing outcomes. These reports will all need to include
information about the core suite of indicators\textsuperscript{123}, supported by local measures and contextualising data to provide a broader picture of local performance.

269. East Dunbartonshire Council noted that everyone needs to be much clearer about the pathways and that most people will be in the community for most of their end-of-life care. It hopes that the creation of the new integration joint boards will help with these links, so that there are good pathways from the hospital into the community, and that voluntary agencies and a range of support agencies will be included. East Dunbartonshire Council’s hope is to minimise the number of readmissions to hospital and ensure good discharge planning. It highlighted that not everybody will need a social worker, but social workers’ core skills focus on good assessment and good support planning. Where possible, there is a need to help people put together flexible packages of support through measures such as self-directed support and direct payments, so that people retain control for as long as possible, right up to the end of life. There is a need to ensure that there is good multidisciplinary working between social workers, occupational therapists, many of whom work in local authorities, and a range of health practitioners.\textsuperscript{124}

270. Palliative care is one of the functions to be delegated to integrated joint boards. It is likely that they will be responsible for commissioning all palliative care services in their areas, both in acute and community settings.

271. The Scottish Government noted that:

\begin{quote}
On integration of health and social care, as the committee will be aware, the integrated joint boards are responsible for palliative care in hospitals and community settings. The set of indicators that has been published for integrated joint boards on health and social care includes measurement of some of the issues in relation to palliative and end-of-life care decisions”.
\end{quote}

125

272. The Committee is disappointed to hear of the issues that patients and their families have experienced when transitioning between services and appreciates how frustrating and stressful this must be for them.

273. The Committee believes that consistent support post-diagnosis must be provided regardless of where a person lives.

274. The Committee therefore notes the potential of integrated joint boards and the Scottish Government indicators to help ensure that people experience a more ‘joined-up’ service going forward. The Committee recommends that the strategic framework identifies how the palliative care activities of integrated joint boards will sit alongside those of health boards, hospices and charities, care providers and local community initiatives.
Role of the general practitioner

275. The Committee has heard evidence that access to palliative care and the service that you receive can have much to do with the ‘individual’ practitioner that you have access to and how they deal with this issue. The Committee also heard that the vast majority of palliative care is provided by generalists and that there was a key role for GPs.

276. The Scottish Partnership for Palliative Care stated that:

> We have some data about general practitioners’ levels of comfort about initiating and conducting discussions on people’s preferences for care towards the end of life, and we know that some GPs are more comfortable about doing that than others. The issue, therefore, might not be where someone lives but whether a particular general practitioner is more comfortable about taking forward discussions on end-of-life care…the kind of palliative care that they get might come down to whether they are admitted to a ward where the staff have been able to access training and support and are comfortable about using their knowledge and skills to provide someone with that care.

277. The RCGPS advised that general practitioners have time limitations placed on them by the system. This affects the care they can provide and they described the affect as “compassion of the care that we can deliver, which can sap the healthcare providers’ morale. If they know that they are not doing the consultations as well as they can, that is not a good place to be.”

278. The Committee considers that GPs are well placed to identify early on deteriorating health in patients and therefore recommends that Framework addresses how GPs might work with other healthcare providers to enable palliative care support to be provided at the earliest opportunity.

279. During the Committee’s scrutiny into the Carers (Scotland) Bill the Committee agreed that the role of carers was very important. Carers will have a large responsibility in helping those with palliative care needs. As recommended in the Stage 1 Carers (Scotland) Bill report, the Committee sees a need for carers to be involved in the discharge of patients from hospitals.

280. The Committee reiterates its request that the Scottish Government sets out how it will ensure that, prior to patients being discharged, hospital staff identify carers and establish that they are “able and willing to provide care.”
Training and education

281. The Committee has heard that at present there is some inconsistency to training and education in palliative care throughout the sectors that provide it. Medical staff at CHAS Rachel House advised that at present bereavement and end of life training is covered in only one lecture. There was a desire for medical staff to attend specialist palliative and end of life care training but that it was not seen as priority and it was not a mandatory course. As such medical staff generally has to complete this training in their own time.

282. The Scottish Government noted that “end-of-life care is one of the most challenging aspects of medical practice. The GMC receives a large number of questions from doctors about this area, and it noted that even experienced doctors say that they sometimes lack the support, the confidence or the skills to effectively communicate some of these issues. We therefore think that one of the key areas of improvement is to support not just doctors but all members of the care team”.

283. As mentioned above, the social care sector has a very important role to play within the palliative and end of life care framework. In the Committee’s report into the Regulation of Care it found that the workforce within this sector was undervalued and underpaid.

284. The RCN advised that it had carried out a survey on end-of-life care in which it asked members key questions about how they provide that care. Almost 8,000 nurses responded within a few days which told them that nurses are passionate about what they do and are concerned about the knowledge that they do not have. Of the survey respondents, almost 3,000 of those 8,000 nurses were hospital staff, and over a third of them dealt with dying people on a daily basis but had never had any formal education in it, and that troubled them. They advised that it is important that they run programmes and that staff are released to attend them or that they encourage reflective practice. It was also advised that there are ways in which people can be educated through learning on the ward or in the environment that they work in, and that reflective practice is a model through which they can enhance the knowledge that exists.

285. In its submission, Marie Curie considered that one of the main priorities in improving access to palliative care for people with all conditions across Scotland was to ensure that health professionals have access to mandatory generalist palliative care training and, importantly, see it as an integral part of their job. Palliative care should be part of core competencies in medical training, regularly updated, and encouraged and demonstrated by senior staff. Marie Curie believes that it is crucial that this applies to all types of health and social care professionals, from GPs to cardiologists. It therefore sees that it would be appropriate to include it in the national healthcare curriculum. It also believes that education and training targeted at health and social care professionals should include:
• Improving palliative care across all settings;
• Ensuring all medical and nursing staff, including those working in the community, know about their local specialist palliative care teams and how to contact them;
• Ensuring better coordination and team working;
• Recognition of and using the right triggers for palliative care; and
• Effective communication between care teams and at points of care transition including use of existing systems, such as the KIS, to communicate care and treatment wishes.

286. Ardgowan Hospice gave details to the Committee of a scheme that they were trying to bring into the local community. The scheme is training those in the community, such as hairdressers, who may be able to assist in signposting potential service users to the hospice and its facilities. They also advised that there were opportunities for care assistants to receive training given their contact with people in the community.

287. Scottish Care discussed how it has tried to make inroads into improving dementia care by setting comprehensive educational standards for specialist or general staff in the sector and certainly in social care. Scottish Care also advised that it is at the point of reviewing the national care standards, and it is looking for them to become more embedded in human rights. It is likely to have a new framework of national care standards within the next two years, and that it is important for palliative and end of life care to be anchored or embedded in that framework going forward.

288. Scottish Care advised that it can apply the things that have made a difference in dementia care to palliative care and attempt to put in place a similar joined-up approach for palliative care and that has become more possible with local integration. It advised that the regulatory bodies and the improvement services are becoming more aligned as well and that Healthcare Improvement Scotland and the Care Inspectorate are working well together and that could be a vehicle for putting in place a standard approach to palliative and end-of-life provision in health and social care settings.

289. A number of those who provide written or oral evidence highlighted that communication skills played a big part of whether good palliative and end of life care was provided or not.

290. Pancreatic Cancer UK noted that “We believe better training and support for healthcare professionals is needed to address variations in the quality and frequency of communication between practitioners and patients. To help address this, healthcare professionals dealing with patients with a terminal, chronic or life-limiting diagnosis should undergo mandatory training in communication, such as the Breaking Bad News course”. 130
291. South Lanarkshire Council offered a similar opinion, in that:

"training varies though within South Lanarkshire Council, there is a clear commitment to staff training and development (e.g.: funded Counselling Skills courses for those practitioners interested in palliative care, dementia training at varying levels and so on). Using a counselling skills approach can be taught and arguably this is something that could be further explored across the fields of health and social care for those practitioners working within palliative care. Care home staff are also trained in supporting people requiring palliation and in offering support to family members.”

292. The Committee heard from NHS Education for Scotland that communication is not always done well. It explained that it has provided lots of communications skills training initiatives over the years and that communication skills are incorporated into undergraduate education for healthcare professionals, and in recent years a lot of effort has gone into improving the approach.

293. NHS Education for Scotland felt that what it perhaps does not do so well with are people who are already working in the system and that some qualified professionals might not have had the input on communication skills at an early stage in their education that more recently qualified people have had. It was felt that the focus is on undergraduate pre-registration education but, when people get into the system, they find that what they learned is not used in practice, and so they can quickly be socialised out of using it.

294. NHS Education for Scotland conducted a literature review on the barriers to using communication skills for people who had attended training. One issue that was highlighted was people’s ability to apply their skills when they started practising. In terms of helping generalists helping them to build confidence and competence and enabling them to use their skills in the work place was important. Whilst the training for that would be intensive, it could be done and NHS Education for Scotland would have to determine how it would facilitate it.

295. The Committee were advised by the Scottish Government that NHS Education for Scotland are represented on the national advisory group and as part of the work to develop the strategic framework for action. They have been asked in this capacity to look at what has worked well in terms of educational resources and what might be required in the future to ensure that there is a range of educational programmes to reach a range of professions across different teams. The Scottish Government also stated “To highlight the point that was made earlier that these issues go beyond cancer, I note that our national improvement plan for stroke includes plans to roll out across the country some specific training resources on how best to assess and provide palliative care as a key dimension of care following a stroke. That is also led by colleagues in NHS Education for Scotland.”
296. The Committee concludes that whilst there are good examples of training and education, there should be mandatory training in palliative care provided across the health care sector.

297. The Committee considers that communications training is a key part of any mandatory training, and that this should be made available to not only new trainees but also to those already working in a sector which provides palliative care. There should be a focus on further supporting skills in palliative care around caring, compassion and empathy.

298. The Committee recommends that the Scottish Government include in its Framework options for training in palliative and end of life care for practising health care professionals as well as those in training. This will support medical professionals to more confidently discuss palliative and end of life care with patients.

3 http://www.scottish.parliament.uk/parliamentarybusiness/CurrentCommittees/91056.aspx
4 http://www.scottish.parliament.uk/parliamentarybusiness/CurrentCommittees/91550.aspx
5 http://www.scottish.parliament.uk/S4_HealthandSportCommittee/Reports/HSS042015R09.pdf
7 http://www.scottish.parliament.uk/S4_HealthandSportCommittee/Inquiries/20151006-CabSecUpdate.pdf
9 http://www.gov.scot/Topics/Health/Quality-Improvement-Performance/peolc/ProgressReport
10 Palliative Care (Scotland) Bill
12 http://www.scottish.parliament.uk/S4_Bills/Assisted%20Suicide/b40s4-introd.pdf
13 Assisted Suicide (Scotland) Bill Policy Memorandum, paragraph 2
16 http://www.palliativecarescotland.org.uk/content/what_is_palliative_care/
17 http://www.palliativecarescotland.org.uk/content/what_is_palliative_care/
19 http://www.who.int/cancer/palliative/definition/en/
20 http://www.palliativecarescotland.org.uk/content/what_is_palliative_care/
22 http://www.palliativecarescotland.org.uk/content/what_is_palliative_care/
23 http://www.who.int/cancer/palliative/definition/en/
25 http://www.scottish.parliament.uk/S4_HealthandSportCommittee/Inquiries/PC028_the_ALLIANCE.pdf
26 http://www.scottish.parliament.uk/S4_HealthandSportCommittee/Inquiries/PC034_Scottish_Independent_Advocacy_Alliance.pdf
27 http://www.scottish.parliament.uk/S4_HealthandSportCommittee/Inquiries/PC044_Scottish_Partnership_for_Palliative_Care.pdf
29 http://www.scottish.parliament.uk/S4_HealthandSportCommittee/Reports/HSS042015R09.pdf
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Annexe A

Extracts from the minutes of the Health and Sport Committee and associated written and supplementary evidence

13th Meeting, Tuesday 28 April 2015
Palliative Care: The Committee took evidence from—
Paul Gray, Director General Health and Social Care and Chief Executive, NHSScotland;
Janice Birrell, Senior Policy/Implementation Manager, and Professor Craig White, Divisional Clinical Lead, Scottish Government.

18th Meeting, Tuesday 2 June 2015
Palliative Care: The Committee took evidence to inform its approach to its forthcoming inquiry on palliative care from—
Rami Okasha, Director of Strategic Development, and Elaine MacLean, Professional Adviser, Palliative Care, Care Inspectorate;
Jacqui Macrae, Head of Quality of Care, Healthcare Improvement Scotland;
Niki Maclean, Director, Scottish Public Services Ombudsman.

21st Meeting, Tuesday 23 June 2015
Palliative care inquiry (in private): The Committee agreed its approach to its inquiry.

24th Meeting, Tuesday 15 September 2015
Palliative Care: The Committee took evidence on 'International comparisons in palliative care provision: what can the indicators tell us?’ from—
Professor David Clark, Wellcome Trust Investigator, School of Interdisciplinary Studies, University of Glasgow.

Written evidence

9th Report, 2015 (Session 4): A report for the Scottish Parliament by Professor David Clark: International comparisons in palliative care provision: what can the indicators tell us?

25th Meeting, Tuesday 22 September 2015
3. Palliative care: The Committee took evidence from—
Amy Dalrymple, Head of Policy, Alzheimer Scotland;
Trisha Hatt, Senior Macmillan Development Manager (Scotland), Macmillan Cancer Support;  
Richard Meade, Head of Policy and Public Affairs, Scotland, Marie Curie;  
Maria McGill, Chief Executive, Children’s Hospice Association Scotland.  
5. **Palliative care (in private):** The Committee agreed to defer consideration of the main themes arising from the oral evidence heard earlier in the meeting.

**Written Evidence**  
- Alzheimer Scotland  
- Macmillan Cancer Support  
- Marie Curie  
- Children's Hospice Association Scotland (CHAS)

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**26th Meeting, Tuesday 29 September 2015**  
3. **Palliative care:** The Committee took evidence from—  
Mark Hazelwood, Chief Executive, Scottish Partnership for Palliative Care;  
Dr David Carroll, Strategic Lead for Palliative and End of Life Care, NHS Grampian;  
Ranald Mair, Chief Executive, Scottish Care;  
David Formstone, Fieldwork Manager, East Dunbartonshire Council Social Work Services, and Beth Hall, Policy Manager, Health and Social Care Team, COSLA;  
Sandra Campbell, Macmillan Nurse Consultant for Cancer and Palliative Care, Royal College of Nursing;  
Dr Euan Paterson, Royal College of General Practitioners Scotland;  
Maggie Grundy, Associate Director, Nursing and Midwifery, NHS Education for Scotland;  
Professor Rob George, President of Association for Palliative Medicine of Great Britain and Ireland. Medical Director St Christopher’s Hospice, Association of Palliative Medicine.  
4. **Palliative care (in private):** The Committee agreed that members should email their views on the main themes arising in the oral evidence heard in the meeting to the clerks.

**Written Evidence**  
- Scottish Partnership for Palliative Care  
- Grampian Palliative and End of Life Care Network Core Group  
- COSLA  
- Royal College of Nursing Scotland  
- Royal College of General Practitioners  
- Association for Palliative Medicine

**Supplementary Written Evidence**  
- Royal College of Nursing Scotland

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Scottish Partnership for Palliative Care

30th Meeting, Tuesday 10 November 2015
Palliative Care (in private): The Committee considered a draft of the report. Various changes were agreed to, and the Committee agreed to consider a revised draft, in private, at a future meeting.

31st Meeting, Tuesday 17 November 2015
Palliative Care (in private): The Committee considered and agreed a draft report on its inquiry into Palliative Care.

List of other written evidence

- A. Muir
- Rebecca Kellett
- Anonymous
- Prof D. Robin Taylor and Dr. Calvin Lightbody
- Strathcarron Hospice
- Friends at the End (FATE) (280KB pdf)
- North Ayrshire Health and Social Care Partnership
- Community Pharmacy Scotland
- Anonymous
- Professor Scott A Murray
- Scottish Social Services Council (SSSC)
- Pancreatic Cancer UK
- Angus Council
- Jan Walker
- Royal College of Paediatrics and Child Health
- Healthcare Improvement Scotland
- Free Church of Scotland
- Scottish Ambulance Service
- NHS Lothian
- Care Inspectorate
- Carole McGregor
- Health and Social Care Alliance Scotland (the ALLIANCE)
- Sue Ryder
- Action for Sick Children (Scotland)
- NHS Ayrshire and Arran
- NHS Forth Valley
- Scottish Independent Advocacy Alliance
- MND Scotland
- National Pharmacy Association
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- Aberlour
- NHS Western Isles
- Royal Pharmaceutical Society in Scotland
- Church of Scotland’s Church and Society Council
- Together for Short Lives
- General Medical Council
- Anonymous
- Aberdeenshire Health and Social Care Partnership
- NHS Borders
- British Psychological Society (BPS)
- South Lanarkshire Council
- Parkinson’s UK in Scotland
- Glasgow City Health and Social Care Partnership
- Glynis Billimore
- Jenny Reid
- Age Scotland
- Inverclyde in Partnership for Palliative Care
- NHS Tayside
- L Geddes
Annexe B

Note of visit to CHAS Rachel House, Kinross and Ardgowan Hospice, Greenock

The note of the visit to CHAS Rachel House can be found on the Scottish Parliament website at the following webpage:

http://www.scottish.parliament.uk/S4_HealthandSportCommittee/Inquiries/CHAS_Rachel_House_Note_of_meeting.pdf

The note of the visit to Ardgowan Hospice, Greenock can be found on the Scottish Parliament website at the following webpage:

http://www.scottish.parliament.uk/S4_HealthandSportCommittee/Inquiries/Ardgowan_Hospice_Note_of_meeting.pdf