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Mr Duncan McNeil MSP
Convener
Health and Sport Committee



By Email.

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Dear Duncan,

Health and Sport Committee – ‘We Need to Talk About Palliative Care’

I would like to offer my gratitude to the Committee for the work they have invested in producing this comprehensive report.

I would like to convey how useful it has been in helping to inform the publication of our Strategic Framework for Action on Palliative and End of Life Care and in helping us work towards a vision where everyone in Scotland who needs palliative care will have access to it.

We have provided some comments on this report.

SHONA ROBISON

RESPONSE TO HEALTH AND SPORT COMMITTEE REPORT ENTITLED ‘WE NEED TO TALK ABOUT PALLIATIVE CARE’

The Scottish Government welcomes the publication of this comprehensive report and note the sixty-three comments and recommendations contained within it. The report both illustrates many of the key challenges involved in enhancing the provision of palliative care in Scotland and provides helpful recommendations into ways in which this can be achieved. We believe that by providing a response to the issues and recommendations raised within the report, this will provide an opportunity to identify commonalities which can aid in the implementation of the Scottish Government’s vision that by 2021, everyone in Scotland who needs palliative care will have access to it.

On 18 December 2015, the Scottish Government launched the Strategic Framework for Action on Palliative and End of Life Care. The publication of ‘We Need to Talk About Palliative Care’ significantly assisted with the preparation of the Strategic Framework and the contents were considered in detail as part of the process of developing the Strategic Framework and will help inform the implementation phase. The Strategic Framework has placed an emphasis on locally developed improvement action and has sought to avoid prescribing specific solutions or reinforcing a ‘command and control’ model of change. For example, the Committee highlighted the need to help ensure that people experience a more ‘joined up’ service going forward. The role of Health and Social Care Partnerships will be key to help ensure that the experience of transitioning between services is improved.

This document provides the Scottish Government’s response to the Committee’s comments and recommendations. It also aims to illustrate how the Committee’s recommendations link with the commitments that have been made within the Strategic Framework for Action in order to fulfil a vision of a Scotland where everyone can receive services that respond to their individual palliative and end of life care needs.

Scottish Government Stakeholder Engagement

The Scottish Government sought feedback from a wide range of relevant stakeholders, including health and social care professionals, representatives from the third sector, service users and interested members of the public to inform the development of the Strategic Framework for Action. In particular, the membership of the Palliative and End of Life Care National Advisory Group and Stakeholder Group, comprised of members from twenty-one different organisations, was particularly helpful in contributing their combined expertise and providing helpful and supportive advice as to how to improve the provision of palliative and end of life care in Scotland. The Scottish Government notes that many of the people and organisations who gave evidence as part of the Committee’s Inquiry into Palliative and End of Life Care are members of one (or both) of these groups and we recognise the passion among those we speak to for delivering high-quality person-centred care

Additionally, three engagement events were held in different parts of Scotland between June and July 2015 and were attended by 181 people. These assisted the process of drafting the Strategic Framework for Action by allowing interested members of the public the opportunity to make the Scottish Government aware of their views and to provide suggestions for improvement.

Structure of Response

The Strategic Framework for Action on Palliative and End of Life Care provides both a high-level vision, and commitments that are intended to provide a solid foundation for future

implementation action over the period 2016-2021. It also recognises that future implementation will be delivered in partnership across the public, independent and voluntary sectors, consequently, it is not possible to provide detailed information regarding the way in which implementation actions will be framed for every commitment. Implementation and improvement science has emphasised the importance of providing high-level aims that can be used to develop localised actions for delivery within existing organisational processes and infrastructure.

Responses to the recommendations and comments contained within the Committee's report are outlined.

Definition

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.

The Scottish Government is grateful for the report's detailed explanation of the different definitions that are used to define the term 'palliative care'. It recognises that there are differing views among relevant stakeholders regarding the use of a single definition of palliative care.

The Scottish Government has set out three overarching aims for the provision of palliative and end of life care:

- Access to palliative and end of life care is available to all who can benefit from it, regardless of age, gender, diagnosis, social group or location.
- People, their families and carers have timely and focussed conversations with appropriately skilled professionals to plan their care and support towards the end of life, and to ensure this accords with their needs and preferences.
- Communities, groups and organisations of many kinds understand the importance of good palliative and end of life care to the well-being of society.

The Scottish Government has included and endorses the following definition of 'palliative care' which was produced by the World Health Organization in 2015 within the Strategic Framework for Action:

"palliative care is an approach that improves the quality of life of patients (adults and children) and their families who are facing problems associated with life-threatening illness. It prevents and relieves suffering through the early identification, correct assessment and treatment of pain and other problems, whether physical, psychosocial or spiritual."

The Scottish Government utilised the following definition of 'end of life care', which has been adapted from a 2015 report produced by the National Institutes of Health, United States of America, within the Strategic Framework:

"end of life care addresses the medical, social, emotional, spiritual and accommodation needs of advanced conditions who are nearing the end of life."

These two definitions have been used, in part, to clarify that palliative care is not solely delivered at the end of life and can be provided to individuals who have been diagnosed with a life-shortening condition throughout their lives.

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'.

The Scottish Government recognises that the provision of palliative and end of life care is provided in a range of forms and, as a consequence, generalists and specialists of various different kinds deliver palliative and end of life care across a diverse range of settings.

The Scottish Government is committed to three quality ambitions to ensure safe, effective and person-centred care¹ and notes that the World Health Organisation has stated that it should be "provided through person-centred and integrated health services that pay special attention to the specific needs and preferences of individuals."

The Strategic Framework for Action emphasises the provision of high quality person-centred care which allows people to have opportunities to discuss and plan for future possible decline in health, preferably before a crisis occurs, and to be supported to retain independence for as long as possible².

The Scottish Government remains committed to driving improvement in the provision of palliative and end of life care and will be seeking to enhance implementation through the identification of a group of individuals who can provide support and facilitate delivery of the required actions to deliver the commitments that have been outlined.

Improving data collection

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.

The Scottish Government recognises there is a need to improve data collection and has made specific commitments within the Strategic Framework for Action to ensure both that improvements are made to the way in which information related to palliative care and end of life care is collected, recorded and shared, and to ensure that assembled data and evidence is effectively used to inform learning and to promote improvement and the spread of high quality care.

The Scottish Government will support the development of improved mechanisms for monitoring and reporting on access, to and the quality of, palliative and end of life care in Scotland.

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.

¹ Scottish Government Healthcare Quality Strategy for NHSScotland available at <http://www.gov.scot/resource/doc/311667/0098354.pdf>

² Scotland's National Outcomes available at <http://www.gov.scot/About/Performance/scotPerforms/outcomes/healthierlives>

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.

The Scottish Government has committed, within the Strategic Framework for Action, to develop and enhance indicators and measures that can be embedded in routine care to support the design, delivery, monitoring, quality improvement and benchmarking of service.

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.

The Scottish Government agrees with this statement and has consequently noted within the Strategic Framework for Action that there is "limited evidence to support which specialist palliative care models are effective and cost effective across different care settings and needs".

We have therefore committed to support clinical and health economic evaluations of new and emerging models of palliative and end of life care delivery.

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. The Committee notes that 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.

The Scottish Government recognises the apparent variation in NHS Board level information. From 1 April 2016 commissioning responsibility for Palliative and End of Life Care will become the responsibility of the newly established Integrated Joint Boards.

The Scottish Government recognises the importance of collecting comparable information regarding spending on palliative care within health boards. For this reason, it has committed, within the Strategic Framework for Action, to support Health and Social Care

Partnerships by providing guidance on their Strategic Commissioning plans in relation to palliative and end of life care services

The Scottish Government recognises the apparent variation in NHS Board level information and is planning to take forward work to further address issues relating to measuring spend on specialist palliative care.

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.

The Strategic Framework for Action recognises that Children's palliative care is part of good medical care and is delivered across primary, secondary and tertiary care as well as in children's hospices. *The Children in Scotland requiring Palliative Care: identifying numbers and needs* that was published in October is helpful if taking forward the Strategic Framework for Action Commitment 4 to support children and families through promoting the development of holistic palliative care for the 0 – 25 years and the other SFA commitments.

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.

The Scottish Government recognises that improvements are urgently needed in the reliable identification of people who might benefit from palliative care. Healthcare Improvement Scotland will be supported to provide Health and Social Care Partnerships with expertise in testing and implementing improvements to identify those who can benefit from palliative and end of life care and in the co-ordination of their care.

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.

The Scottish Government is committed to developing a culture of openness and transparency in healthcare that welcomes feedback and uses it as a tool for learning and improvement. We agree that people using services and their families have a central role to play in improving services. The Scottish Government is working with partners including the Scottish Health Council, Healthcare Improvement Scotland, COSLA, the ALLIANCE and other third sector partners to develop the 'Our Voice' framework, which aims to enable people with lived experience of health and care services to engage purposefully with health and care providers to improve and develop services.

Scottish Government colleagues are also taking forward early work with as NHS Board to establish a VOICES type survey to complement work they are already undertaking locally to capture real-time feedback from families and carers.

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.

The Scottish Government recognises the benefits of the VOICES survey and regards it as a well-developed survey instrument. Discussions are currently underway regarding new piloting of VOICES in specific local settings. This small local testing will focus on localised approaches and if and how these might aggregate into a national approach to help drive improvement.

Helping the Conversation

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.

The Strategic Framework for Action commits to support greater public and personal discussion of bereavement, death, dying and care at the end of life. Within this commitment, a specific emphasis has been placed on supporting local plans to enhance the public health focus of health professionals on palliative care.

We are also committed to support the workforce and will commission NHS Education Scotland and the Scottish Social Service Council to develop a new palliative and end of life care Educational Framework. This will address the needs of the health and social care workforce and will focus on developing an integrated and collaborative approach to educational provision.

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.

We recognise the importance of placing an emphasis on ensuring that a culture of openness about dying, death and bereavement is developed to ensure that appropriate conversations regarding care and support preferences can take place.

There is an opportunity to more effectively align palliative care conversations and anticipatory care planning with the wider concept of Collaborative Care and Support Planning. This approach supports and enables people to articulate their own needs and decide on their own priorities, through a process of joint decision making, goal setting and action planning. We have commissioned work which focuses on care and support planning conversations through the House of Care work and the Living Well in Communities Programme and the development of tests of change as part of new models of primary care.

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.

The Scottish Government recognises that it must ensure that it has a trained workforce to deliver palliative and end of life care and that informal carers, family members and volunteers also have access to support, education and guidance that can enhance their contribution. The Scottish Government has therefore made a specific commitment to developing a new palliative and end of life care educational framework. This will address the needs of the health and social care workforce and will be focused on fostering an integrated and collaborative approach to educational provision.

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.

As part of the efforts to develop a culture of openness about dying, death and bereavement in Scotland, the Scottish Government recognises that utilising terminology in an appropriate and effective manner is a matter of key importance. Many of the dimensions of palliative and end of life care form part of the core values and approach of what constitutes high quality care. The Scottish Government will support policy teams working across health and social care to consider how person-centred care initiatives can support conversations about care preferences.

The importance of early identification of those who require access to palliative and end of life care is well recognised. Ensuring appropriate and timely conversations take place enables people to record their wishes and care and support preferences in the event of a future deterioration. The Scottish Government supported piloting of the Institute for Healthcare Improvement Conversation Ready work in Scotland. These pilots focussed on the challenges faced by health and care professionals responsible for initiating, capturing and recording compassionate end of life conversations with patients and their families/carers.

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.

The Scottish Government recognises and has acknowledged the benefits obtained through the use of the Supportive and Palliative Care Indicators Tool within the Evidence Summary that accompanied the Strategic Framework for Action. Tools and approaches to identify people who require palliative care should be identified locally and implemented as part of local implementation plans.

Recording Systems

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.

The Scottish Government agrees with the committee regarding the need to simplify access to palliative care and has made a commitment, within the Strategic Framework to Action, to improving the way in which information relating to palliative and end of life care is recorded and shared.

The Scottish Government has also stated, within the Strategic Framework for Action, that access to the Key Information Summary and the Emergency Care Summary needs to be maximised.

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.

The Living Well in Communities improvement work being delivered by Healthcare Improvement Scotland is taking forward specific focussed work on Anticipatory Care Planning (or as it is increasingly being referred to, care and support planning). Dr Stuart

Cummings and Ms Janette Barrie have been appointed to provide dedicated clinical support to this commencing in their posts with HIS in January this year.

The Scottish Government has committed, within the Strategic Framework for Action, to improving the ways that information is recorded and shared by seeking to ensure that the requirements for future e-Health systems support the effective sharing of individual Anticipatory Care Planning conversations and care preferences. The mechanics involved in achieving this will be considered by the future Implementation Group.

Access to palliative care

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.

The range of commitments set out in the Strategic Framework for Action aims to ensure that by 2021 where everyone who can benefit from palliative care in Scotland will receive it – no matter what their circumstances.

We will support and co-ordinate the resources and infrastructure required to develop specific implementation plans focused on the measurement of change. This work will set out the timescales required across a range of organisations involved locally and nationally in delivering the commitments outlined in this Framework.

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'.

The Strategic Framework for Action places a focus on ensuring that everyone who needs palliative care will have access to it. This will be achieved, in part, through targeted work on improving the educational provision which relates to end of life and palliative care. The Scottish Government has commissioned NHS Education for Scotland and the Scottish Social Services Council to develop a new palliative and end of life care Educational Framework which will include the development of defined core competencies in palliative and end of life care expected for all roles within the health and social care system. We will seek to ensure that health and social care professionals have the knowledge, skill and competence to identify people who will benefit from palliative care and to deliver elements of care that address identified needs

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.

All of the commitments in the Strategic Framework for Action aim to ensure that everyone who needs palliative care will have access to it. For example the improvements in measurement and monitoring of palliative and end of life care provision will be delivered through nationally sponsored work and existing accountability and performance monitoring arrangements of delivery organisations.

We have also committed to improving the ways that information is recorded and shared by seeking to ensure that the requirements for future e-Health systems support the effective sharing of individual end of life/care and support preferences.

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.

The Scottish Government has committed, within the Strategic Framework for Action, to improving the ways that information is recorded and shared by seeking to ensure that the requirements for future e-Health systems support the effective sharing of individual end of life/care and support planning conversations and care preferences.

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.

The Scottish Government has committed, within the Strategic Framework for Action, to support children and families by promoting the further development of holistic palliative care for the 0 - 25 year age group, recognizing that many of their needs may differ from those of adults.

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.

The Scottish Government recognises the vital importance of respite care and fully supports the provision of short breaks for individuals with care needs and the people who care for them.

Officials from Scottish Government will continue working with CHAS and other interested parties to explore available options for respite breaks.

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 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.

Scottish Government has already commissioned a mapping exercise of specialist palliative care facilities, resources and services that are available in Scotland and it is expected that these data will be available in the Spring. It is recognised that this will only provide part of the picture. Through implementation of the Strategic Framework for Action and working with Health and Social Care Partnerships to develop and test local implementation plans it is hoped that will be able to build on the specialist palliative care service information in order to ensure availability of signposting to local services.

Where is palliative care provided?

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.

Local authorities allocate care on the basis of an individual's assessed needs. It's clear that no-one should have a 15 minute or shorter visit when it is not appropriate. While, for instance, a medicine prompt might be an appropriate reason for a short visit, it would be inappropriate to expect a carer to be able to get someone up, washed, and give them their breakfast in such a short time.

The Scottish Government have developed a new joint inspection regime to ensure that people get the level of support, through free personal care, that they have been assessed as needing, and that the quality is no less than the people of Scotland deserve. Inspections will include the commissioning processes by councils that determine the volume and length of visits needed to deliver safe, compassionate care services for Scotland's older people.

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 baseline funding, such as the 12.5 per cent indicated by CHAS, will be met for hospices going forward.

NHS Tayside commissions services from CHAS on behalf of all 14 NHS Boards in Scotland. There has been a programme of joint meetings between NHS Tayside and CHAS colleagues and it is expected that the review and confirmation of agreed running costs will be concluded by the end of this financial year. Scottish Government officials have received positive updates from both NHS Tayside and CHAS colleagues on these discussions.

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.

Scottish Government officials met with Children's Hospice Association Scotland (CHAS) Officials on 24 November 2015 to discuss current and possible future commissioning arrangements.

As part of the Palliative and End of Life Care Strategic Framework for Action, we will support clinical and cost effectiveness evaluations of new and emerging models of palliative care delivery. This will inform national and local planning and commissioning of both children and adult hospice services.

I have also asked officials to plan a review of hospice funding as part of implementation of the Strategic Framework for Action to look at addressing the disparity between children and adult hospices.

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.

The Scottish Government recognises that local implementation is needed which will appropriately identify, test and develop improvement action in relation to referral routes to hospice services.

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.

In contributing to supporting and achieving the national health and wellbeing outcomes, the Care Inspectorate and Healthcare Improvement Scotland jointly inspect and review the impact of strategic commissioning of services and the effectiveness of strategic plans for care at home service users, which can include palliative care. They are currently reviewing the methodology for these inspections with a view to improving care at home services and the outcomes for people using a service. This will commence no earlier than April 2017

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.

Because of the potential size of the sustainability and seven day services work we have taken a phased approach to the Sustainable Seven Day Services programme.

The first phase focussed on a number of clinical areas such as acute surgery, major trauma, diagnostics etc.

Palliative care was not one of the phase one areas and we are not taking any forward any specific work on it, however it is clearly implicit in the work the Taskforce are looking at in terms of availability of senior decision making and support services such as diagnostics where a lack of services at the weekend or out of hours could impact on the quality of service.

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.

The Scottish Government welcomed the publication of Pulling Together: Transforming Urgent Care for the People of Scotland. On 30 November the Scottish Government announced £1m of immediate funding towards testing the proposed new model of urgent care including development of Urgent Care Resource Hubs. In response to this the Scottish Government have invited all health board areas to share their test proposals and so far have met with Ayrshire and Arran, Tayside, Highland, Grampian and Lothian. These immediate tests will be designed from a national and local perspective, including rural and urban dimensions as well as improving services for a range of specific groups.

In addition to developing the testing programme, we have written to Integrated Joint Boards requesting their views on how they would, in collaboration with their partners, health boards and local authorities, deliver the proposed new model of urgent care.

The testing programme together with responses received from IJBs will inform the National Implementation Programme for transformation of urgent care services, which we aim to publish in the Spring.

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.

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.

The Scottish Government has committed to creating the conditions, through implementation of the ten commitments within the Strategic Framework for Action, in which substantial improvements can be made in the coordination of care between services. The Strategic Framework contains a specific commitment to provide guidance to Health and Social Care Partnerships with the development of the content of their Strategic Commissioning plans in relation to palliative and end of life care services.

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.

The Scottish Government recognises the importance of the role that Health and Social Care Partnerships will have in the commissioning and delivery of palliative and end of life care services. We believe that the focus must be on how health and social care integration will improve the organisation and delivery of palliative and end of life care within hospitals and communities, including hospices, care at home, in care homes and other relevant social care services. Consequently, the Scottish Government has committed to providing guidance to support Health and Social Care Partnerships with the development of the content of their Strategic Commissioning plans in relation to palliative and end of life care services.

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.

The Scottish Government agrees that GPs have a key role in identifying deteriorating health in patients and that they work with other healthcare providers to enable palliative care support to be provided at the earliest opportunity. We see this aim as being supported by both the existing Directed Enhanced Service for palliative care, with its recent focus on non-malignant palliative and end of life care, and the intended direction of travel for the General Medical Service contract (future role of the GP to focus on complex care, undifferentiated illness and quality and leadership), where the GP will be supported and enabled to be more proactively involved in meeting the needs of patients with complex care needs, particularly including particularly those patients with palliative and end of life care needs.

As part of work on Transforming Nursing Roles, the Chief Nursing Officer Directorate are in the process of reviewing and refocusing the role of the District Nurse (DN). Core components of this role will centre around; frailty, intermediate and anticipatory care, palliative care and care at the end of life. A key part of this work is strengthening the DN role around prevention and early intervention and in working with General Practice in trying to ensure patients are nursed at home and that all care planning, including palliative care, starts at the earliest opportunity in partnership with the family and other appropriate agencies. This will include ensuring the DN is at the heart of care management and the commissioning of all care and services.

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.

An amendment currently under consideration in the Carers (Scotland) Bill [as amended at stage 2 shows] is

Part 4 – CARER INVOLVEMENT

25 (4A) Each health board must in particular take such steps as it considers appropriate to ensure-

- (a) that when planning the discharge of a person from hospital it-
- (i) informs any carer who provides, or intends to provide, care for that person of the planned discharge, and
 - (ii) involves any such carer in planning the discharge, and
 - (iii) takes account of the views of any such carer in making decisions about the discharge of the person, and
- (b) that such planning begins as soon as reasonably practicable after the admission of the person to hospital.

Training and Education

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.

The Scottish Government recognises the importance of providing appropriate training in palliative care across the health and social care landscape and has therefore additionally committed to supporting the development of defined core competencies in palliative and end of life care expected for all roles within the health and social care system