Strategic Framework for Action on Palliative and End of Life Care

2016-2021



The Scottish Government

December 2015

The Scottish Government
Riaghaltas na h-Alba



Foreword

Each year around 54,000 people die in Scotland. I have seen first-hand the outstanding care that is provided to many of these people through speaking with people and their families and through my visits to hospitals, GP surgeries, care homes, hospices and other specialist palliative care services. I am proud of the considerable improvements that the Scottish Government has put in place, with 14% more doctors and 25% more nurses working to provide specialist palliative care services since 2009. However, I recognise that more and more people are living with long term conditions and many of those who could currently benefit from palliative and end of life care are not receiving it. I am deeply committed to supporting improvements that ensure that high quality palliative and end of life care is available to all who can benefit from it.

In 2014 the World Health Assembly – the governing body of the World Health Organisation - passed a resolution requiring all governments to recognise palliative care and to make provision for it in their national health policies. This Strategic Framework for Action is a response to that call. It builds on many actions and policies already in place and sets out the goals, challenges and direction for future improvement. The *Strategic Framework for Action on Palliative and End of Life Care* sets out an ambitious, but fully achievable set of commitments that the Scottish Government will work with partners to implement to help ensure that everyone in Scotland gets the care they need when time is becoming shorter.

This Strategic Framework outlines the areas where action needs to be taken to ensure that by 2021 everyone who needs palliative care will have access to it. Building on the work of *Living and Dying Well* (2008), the Framework will be supported by £3.5 million funding over four years which will be used to drive improvement across the sector and support targeted action on training and education. This will be made possible through the promotion of collaborative working to harness the knowledge, skill and vision of the many extraordinarily passionate individuals who work and volunteer to help those with palliative care needs. Staff from health, care, independent and third sector organisations will be given the support they need to improve the delivery of palliative and end of life care in their sector.

The Framework will also work to drive a new culture of openness about death, dying and bereavement. We will work to support organisations in developing a national conversation which engages with this topic that I fully understand is difficult yet vital to discuss. We will also seek to extend this openness to the appropriate sharing of information to ensure that the people of Scotland experience an integrated health and social care system that fully takes into account their end of life care preferences.



Shona Robison MSP
Cabinet Secretary for Health, Wellbeing & Sport





These are inspiring times for palliative and end of life care in Scotland. This *Strategic Framework for Action on Palliative and End of Life Care* is published in a year when we have seen unprecedented public discussion about end of life issues – in the Scottish Parliament, in the national media, in expert reports, briefing documents, consultation submissions and in the work of leading researchers.

As a society we are facing a growing need for appropriate care in the face of ageing, life limiting illness and death. We are challenged by the scale and complexity of this - but we have substantial assets and expertise within Scotland with which to respond. The Framework builds on these, to map out a vision where everyone who can benefit from palliative care in Scotland will receive it – no matter what their circumstances.

To achieve this vision, many people, organisations and agencies will have to work together in a culture of collaboration and with a passion for improvement.

We would like to express our gratitude to all those who have contributed to the development of this Strategic Framework for Action. We would especially like to offer our thanks to all of those who have contributed in their capacity as members of the Palliative and End of Life Care National Advisory Group and Stakeholder Group (detailed in Annex C) or through attending one of the three engagement events.

Palliative and end of life care are now issues of major public interest. The Scottish Government has made its commitments clear. The Strategic Framework for Action and accompanying evidence summary lay out the elements in the work we must now do to create a more compassionate Scotland - and to give people the best care we can at the end of their lives.



Professor David Clark
Consulting Editor, Strategic Framework for Action
University of Glasgow



Professor Craig White
Chair, National Advisory Group for Palliative & End of Life Care
Scottish Government

Executive Summary

Vision

By 2021, everyone in Scotland who needs palliative care will have access to it.

Palliative and End of Life Care Aims

- 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.

Palliative and End of Life Care Outcomes

- People receive health and social care that supports their wellbeing, irrespective of their diagnosis, age, socio-economic background, care setting or proximity to death.
- People have opportunities to discuss and plan for future possible decline in health, preferably before a crisis occurs, and are supported to retain independence for as long as possible.
- People know how to help and support each other at times of increased health need and in bereavement, recognising the importance of families and communities working alongside formal services.
- People access cultures, resources, systems and processes within health and social care services that empower staff to exercise their skills and provide high quality person-centred care.

Palliative and End of Life Care Objectives

We will achieve this by:

- Improved identification of people who may benefit from palliative and end of life care.
- An enhanced contribution of a wider range of health and care staff in providing palliative care.
- A sense among staff of feeling adequately trained and supported to provide the palliative and end of life care that is needed, including a better understanding of how people's health literacy needs can be addressed.
- A greater openness about death, dying and bereavement in Scotland
- Recognition of the wider sources of support within communities that enable people to live and die well.
- Greater emphasis in strategic plans, research activities and improvement support programmes on enhanced access to and quality of palliative and end of life care.

Commitments

The Scottish Government commits to working with stakeholders to:

1. Support Healthcare Improvement Scotland in providing Health and Social Care Partnerships with expertise on testing and implementing improvements in the identification and care co-ordination of those who can benefit from palliative and end of life care.
2. Provide strategic commissioning guidance on palliative and end of life care to Health and Social Care Partnerships.
3. Support the development of a new palliative and end of life care educational framework.
4. Support and promote the further development of holistic palliative care for the 0-25 years age group.
5. Support the establishment of the Scottish Research Forum for Palliative and End of Life Care.
6. Support greater public and personal discussion of bereavement, death, dying and care at the end of life, partly through commissioning work to facilitate this.
7. Seek to ensure that future requirements of e-Health systems support the effective sharing of individual end of life/Anticipatory Care Planning conversations.
8. Support clinical and health economic evaluations of palliative and end of life care models.
9. Support improvements in the collection, analysis, interpretation and dissemination of data and evidence relating to needs, provision, activity, indicators and outcomes in respect of palliative and end of life care.
10. Establish a new National Implementation Support Group to support the implementation of improvement actions.

Implementation Support

By April 2016 these commitments will have informed and be reflected in implementation and improvement plans that will be supported by a national implementation support group which will:

- Oversee the enhancements in improvement support capacity.
- Oversee the development of a new educational framework.
- Establish mechanisms to share learning and improvements across the country.
- Support the development of locally owned improvement and implementation plans that will outline the actions being taken and improvements being made.
- Provide an annual learning and improvement report that will outline the ways. in which improved care and outcomes have been delivered.

Who Will Support Implementation

The Strategic Framework now requires support and action from a wide range of statutory, independent and third sector organisations nationally and locally.

The development of the framework has been greatly assisted by the membership of the Palliative and End of Life Care National Advisory Group and Stakeholder Group. We are committed to ensuring that the membership of these groups, as well as the public at large, will be able to contribute to future implementation actions.

Introduction

1. The 2020 Vision for Health and Social Care describes a health and care system that is focused on prevention, anticipation and supported self-management. We want people to be supported to live – and die – well, on their own terms with whatever health conditions they have.

2. The *Strategic Framework for Action on Palliative and End of Life Care* sets out the approach and our shared vision for people in Scotland where by 2021 everyone who needs palliative care will have access to it.

3. This will mean:

- 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.

To achieve this, those involved in the provision of palliative care in Scotland must be supported with how to:

IDENTIFY everyone who might benefit from palliative care	**INVOLVE** people in discussions about palliative care - what it is and how it can be made more widely available
INCLUDE all diagnoses, ages and groups within the commissioning and delivery of care	**INVESTIGATE** how well palliative and end of life care is being delivered
INDIVIDUALISE every person's care to their needs	**INTEGRATE** relevant services and resources
IMPROVE and develop services continually	**INNOVATE** to respond to emerging needs

This Framework outlines the areas where the Scottish Government will work with partners to support collaboration and co-operation across organisations, reflecting our approach to improving public services and the move away from managerialist approaches. It is the start of a process that will see the development of an

implementation plan that will outline specific actions, timescales and roles for all the organisations that will need to work together to make the vision a reality for everyone.

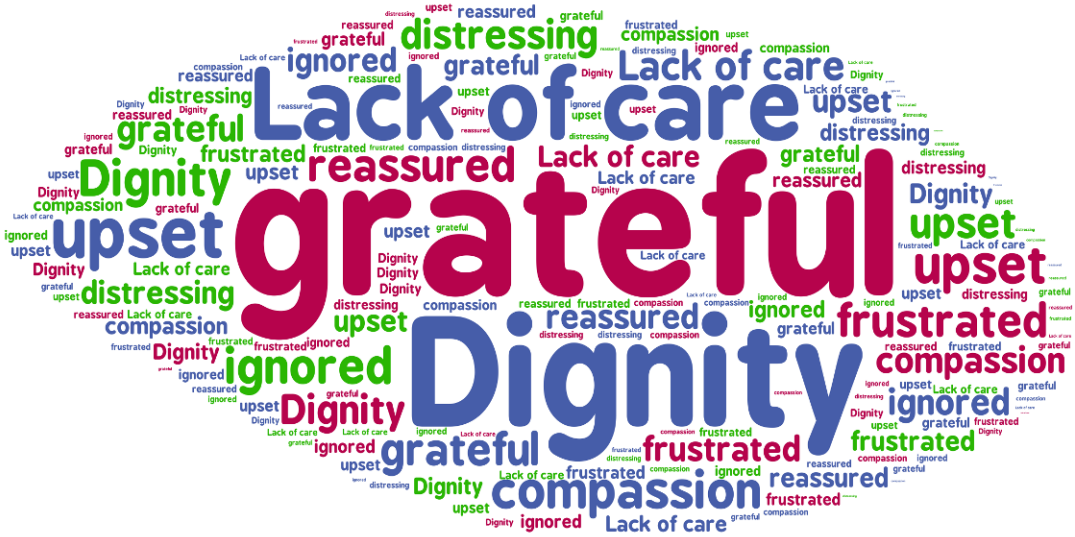
The approach of the Framework is to help ensure that the wellbeing of people, families and carers is supported, even as health declines. It should enable people to die well, and support those who are bereaved. The Framework outlines the Scottish Government's commitments to support staff to implement a co-ordinated series of actions that are focused on improving access to high quality palliative and end of life care.

> "I did feel a bit abandoned and a bit scared… the middle of the night is a very terrifying place to be in when you're not sure what to do." (*Bereaved carer of husband who lived with cancer - from Marie Curie's Changing the Conversation http://www.mariecurie.org.uk/change)*

The Framework sets out the context, challenges and commitments that will support the improvements required in the delivery of palliative and end of life care in Scotland. An accompanying evidence summary document sets out the issues and challenges in more detail and should be used to inform the development of improvement plans and change processes.

The Framework sets out the Scottish Government's commitments in support of the continuous improvement in the quality of palliative and end of life care, reflecting the commitment to the quality ambitions outlined in the Healthcare Quality Strategy (2010), the National Performance Framework Outcomes and also the National Health and Wellbeing Outcomes (Annex A). It is part of the Scottish Government's transformational change programmes and is consistent with the emphasis that will feature in the National Clinical Strategy.

Context



This 'Wordle' diagram was generated from text provided from the website *patientopinion.org.uk* from stories that were published which relate to palliative care in Scotland. This diagram relates to the words that were mentioned when people described how they felt about palliative and end of life care.

4. In Scotland around 54,000 people die each year and over 200,000 people are significantly affected by the death of a loved one. In general we are dying at older ages, sometimes accompanied by frailty, dementia and multiple other conditions. Driven by population growth, the number of people dying each year will begin to rise from 2015. By 2037 the number of people dying each year will have have gone up by 12% to 61,600. It is thought that up to 8 out of 10 people who die have needs that could be met through the provision of palliative care.

5. A number of definitions have been proposed to define palliative care, including two by the World Health Organisation (Annex B). Palliative care is essentially support to prevent and relieve pain and suffering throughout any serious illness as well as where death is impending, and in bereavement. It starts with families and communities, working with health and social care professionals, some of whom are specialists in palliative care. Palliative care is an approach that improves the quality of life of adults, babies, children and their parents, families and carers when they are facing problems associated with life-limiting conditions. It works through early identification, assessment and treatment of pain and other physical, psychological, social or spiritual problems.

6. Palliative care can be delivered in any setting but is mainly organised through primary and home care, nursing/care home, hospice and hospital services. It has proven value, is a human rights, public health and equalities issue, and the need for it is growing with the ageing population. Scotland has a good record of delivering high quality palliative and end of life care. There are strong primary and secondary care systems, supportive communities, a vibrant third and independent sector along with access to a wide range of information and help through print and electronic media.

7. We know however that there are currently people in Scotland who could benefit from palliative care who do not receive it. There will also be a rising demand for palliative care services in the future.

> "My overwhelming impression is that there's lack of consistency. It all depends where you live." (*Bereaved carer of daughter who lived with cancer - from Marie Curie's Changing the Conversation http://www.mariecurie.org.uk/change)*

8. Palliative care and care at the end of life needs to be responsive to the changing preferences and priorities of people with advanced illness and their carers. All health and care workers require an appropriate level of knowledge and skill in palliative and end of life care. Holistic high quality care must be delivered for everyone in accordance with the appropriate legal, professional, clinical and care standards.

9. Meeting more people's palliative care needs in Scotland will require greater support to help people talk sensitively, openly and honestly about deteriorating health and death. Communication can sometimes be poor and anticipatory care planning has not always been as good as it could have been. Documenting, reviewing, updating and sharing decisions and preferences makes it more likely

that the care provided will be person-centered and reflect what someone needs and wants.

10. Currently a person's diagnosis or condition significantly influences the care and support they can access, where they are cared for and funding for their support and accommodation. There can also be inequalities arising through socioeconomic and educational disadvantage, and associated with particular individual characteristics such as age, ethnic group, religion or belief and sexual orientation. Particular groups in society may also be disadvantaged, such as people who are in prison or who are part of a travelling community. There are also issues when considering the transition to adult services for young people with palliative care, respite and support needs.

> "Watching your mum deteriorate and become a shell of her former self with a degenerative palliative brain disease is awful, however the comfort given knowing that my mum is loved and cared for goes a long way." (*Comment submitted to Patient Opinion - http://www.patientopinion.org.uk)*

11. Palliative care must also involve consideration of the needs of the thousands of unpaid carers, their families and others within communities who support people at the end of their lives. This includes parents who become full-time carers when looking after their child with a life-shortening condition and the emotional impact this can have on them and the child's siblings.

Challenges

12. **Measurement and Monitoring -** It is not currently possible to describe comprehensively how palliative care is being provided or experienced by those who receive it across Scotland. Measurement and monitoring are not yet embedded in routine clinical processes and practice. This makes it difficult to identify where to focus improvement support or describe the ways in which existing work is making a positive difference to individual and family outcomes.

13. **Medicalisation of Death -** Current attitudes to death and dying influence the ways in which the health and social care delivery system can meet Scotland's growing need to provide more people with access to improved palliative care. Social and cultural change has resulted in a 'death-denying culture' and the medicalisation of death. An entire generation has come to expect that all aspects of dying will be taken care of by professionals and institutions, potentially undermining personal and community resilience in coping with death, dying and loss as part of the 'cycle of life'.

14. **Communication -** Not everyone wishes to openly discuss death and end of life issues. Information provision, health literacy, culture and belief systems will all influence whether and how such discussions take place. Professionals need to be sensitive to people's beliefs and also their health literacy needs, so that barriers to communication can be removed. People may wish to be more involved in conversations about care and support planning than their confidence, understanding, knowledge and skills currently allow them to be.

> "The nursing staff offered every opportunity to be with our mum in her final days, they made sure she remained comfortable and she was treated with dignity throughout her short stay. The medical staff also took time to clearly explain her deterioration and what to expect in the coming days." *(Comment submitted to Patient Opinion - http://www.patientopinion.org.uk)*

15. **Education -** Generalists and specialists (of various kinds) deliver palliative and end of life care across many settings. Clarity about their differing roles and responsibilities is lacking. Challenges have also been apparent in accessing education and training, often due to difficulties in releasing staff from their clinical and caring duties.

16. **Identification** – There are variations in access to palliative care by condition, age, location, ethnicity and the identification challenges posed by multiple medical conditions. Longer periods spent living with life-limiting illness can make it difficult to know when the time is right for professionals to introduce a palliative care approach. This can present difficulties for the families of those involved. Improvement actions focused on these areas will be essential to ensure that everyone has access to high quality palliative care.

Commitments

The Scottish Government is committed to working in partnership to support a range of improvements in the delivery of palliative and end of life care in Scotland. These commitments focus on broadly defined aims where evidence and feedback have demonstrated that actions need to be targeted.

The Scottish Government's commitments will support:

- Improved identification of people who may benefit from palliative and end of life care.
- An enhanced contribution of a wider range of health and care staff in providing palliative care.
- A sense among staff of feeling adequately trained and supported to provide the palliative and end of life care that is needed, including a better understanding of how people's health literacy needs can be addressed.
- A greater openness about death, dying and bereavement in Scotland.
- Recognition of the wider sources of support within communities that enable people to live and die well.
- Greater emphasis in strategic plans, research activities, quality of care reviews and improvement support programmes on enhanced access to high quality palliative and end of life care.

The delivery of these aims will be made possible through:

- A series of implementation plans that outline local improvement aims.
- A set of actions focused on change and improvement.
- Nationally co-ordinated monitoring and support of quality improvement activity.
- Additional funding of £3.5 million

This will ensure:

- People receive health and social care that supports their wellbeing, irrespective of their diagnosis, age, socio-economic background, care setting or proximity to death.
- People have opportunities to discuss and plan for future possible decline in health, preferably before a crisis occurs, and are supported to retain independence for as long as possible.
- People know how to help and support each other at times of increased health need and in bereavement, recognising the importance of families and communities working alongside formal services.
- People access cultures, resources, systems and processes within health and social care services that empower staff to exercise their skills and provide high quality person-centred care.

Improvements are urgently needed in the reliable identification of people who might benefit from palliative care. More conversations about future care preferences and arrangements and improved arrangements for accessing information to deliver high quality palliative and end of life care will be required.

Commitment 1. We will support Healthcare Improvement Scotland in providing 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.

Health and Social Care Partnerships will play an increasingly important role in the commissioning and delivery of palliative and end of life care services. Commissioning plans should reflect the importance, value and specific contributions of palliative and end of life care in delivering the national outcomes for health and social care. 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.

Commitment 2. We will provide 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.

Scotland 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. This 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. This will be linked to descriptors of attainment.

Commitment 3. We will support the workforce by commissioning NHS Education for Scotland and the Scottish Social Services 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 be focused on fostering an integrated and collaborative approach to educational provision.

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. Currently most end of life care for children is delivered in the hospital environment. The prevalence of children and young people (aged 0 – 25 years) with a life-shortening condition in Scotland has risen between 2003/4 and 2013/14.

Commitment 4. We will 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.

A strategic approach needs to be taken to develop a sustainable and innovative national programme of palliative and end of life care research that directly informs clinical practice and policy by focusing activity on priority areas. A new research forum will provide a platform to share emergent examples of good practice and experience of what works, for whom and why, facilitating knowledge exchange, informing evidence-based decision making and driving quality improvement.

Commitment 5. We will strengthen and co-ordinate research and knowledge exchange across regions, institutions and disciplines by taking further action to support the establishment of a Scottish Research Forum for palliative and end of life care.

There are opportunities for strategic engagement to (re)frame public discourse around death, dying and loss. The goal is to spread at scale a culture of openness about dying, death and bereavement in Scotland, finding opportunities to work with social and mass media and wider publics, across educational establishments, business, faith groups, community organisations and creative industries. It is now widely accepted that palliative and end of life care are matters of public health. Fostering public health interventions to support palliative and end of life care will be important to the success of the Strategic Framework for Action.

Commitment 6. We will support greater public and personal discussion of bereavement, death, dying and care at the end of life. This will include commissioning work from public service agencies outside of health and social care such as schools, colleges and prisons. Local plans to enhance the public health focus of public health professionals on palliative care will also be supported.

There is a need to identify how electronic systems can best ensure that care planning conversations are effectively recorded and appropriately shared through electronic systems. The future requirements of electronic systems for wider access to information, extended information content and new functions, such as write access by multiple sources, must take account of requirements for improvement in

palliative and end of life care. Continued access to the Key Information Summary and the Emergency Care Summary needs to be maximised.

<u>Commitment 7</u>. We will improve 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/Anticipatory Care Planning conversations and care preferences, while also addressing the need for improvement in the systems that are currently used.

There is limited evidence to support which specialist palliative care models are effective and cost effective across different care settings and needs. Adult palliative care clinical guidelines have been developed, though variation in implementation of these exists and reliability of implementation needs to be enhanced.

<u>Commitment 8</u>. We will support national and local planning and commissioning by supporting clinical and health economic evaluations of new and emerging models of palliative and end of life care delivery.

There is a need 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 services. These should ensure that people's experience is appropriately captured and informs future development. Data on quality of care must be capable of outlining the way in which access to high quality palliative and end of life care is continuously improving across Scotland for everyone.

The way in which these data will be used should be aligned with existing performance and national health and wellbeing outcomes and related delivery frameworks, outlining the ways in which improvement actions across national programmes contribute to improved palliative and end of life care.

<u>Commitment 9</u>. We will ensure that data and evidence – including people's accounts of their experience of care – is used effectively to inform learning, improvement and the spread of high quality care by supporting improvements in the collection, analysis, interpretation and dissemination of data and evidence relating to needs, provision, activity, indicators and outcomes in respect of palliative and end of life care in Scotland.

Implementation

We will establish a National Implementation Support Group to support and co-ordinate the resources and infrastructure required to develop specific implementation plans focused on the measurement of change.

These will be developed by April 2016 and will outline the aims, specific actions and timescales required across a range of organisations involved locally and nationally in delivering the commitments outlined in this Framework. This Group will also, through existing accountability mechanisms and arrangements, provide advice to the National Advisory Group for Palliative and End of Life Care on the effectiveness of implementation against the Scottish Government's commitments.

This new National Implementation Support Group will report to the National Advisory Group for Palliative and End of Life Care and have strong representation from the Palliative and End of Life Care Stakeholder Group.

This Group will not be a monitoring group. It will focus on facilitating learning and identifying the actions required to support the spread of improvement across the country. It will produce an annual national overview outlining the learning and improvements undertaken against each of the Scottish Government's commitments.

Commitment 10. We will support the implementation of improvement actions to deliver these commitments by establishing a new National Implementation Support Group involving a wide range of partners.



This Wordle diagram was generated from text provided from the website *patientopinion.org.uk* from stories that were published which relate to palliative care. This diagram relates to the words that were mentioned when people described what was positive about their experience of palliative and end of life care in Scotland.

Annex A

National Health and Wellbeing Outcomes

The National Health and Wellbeing Outcomes are high-level statements of what health and social care partners are attempting to achieve through integration and ultimately through the pursuit of quality improvement across health and social care.

By working with individuals and local communities, Integration Authorities will support people to achieve the following outcomes:

- **Outcome 1:** People are able to look after and improve their own health and wellbeing and live in good health for longer.
- **Outcome 2:** People, including those with disabilities or long term conditions, or who are frail, are able to live, as far as reasonably practicable, independently and at home or in a homely setting in their community.
- **Outcome 3.** People who use health and social care services have positive experiences of those services, and have their dignity respected.
- **Outcome 4.** Health and social care services are centred on helping to maintain or improve the quality of life of people who use those services.
- **Outcome 5.** Health and social care services contribute to reducing health inequalities.
- **Outcome 6.** People who provide unpaid care are supported to look after their own health and wellbeing, including to reduce any negative impact of their caring role on their own health and well-being.
- **Outcome 7.** People using health and social care services are safe from harm
- **Outcome 8.** People who work in health and social care services feel engaged with the work they do and are supported to continuously improve the information, support, care and treatment they provide.
- **Outcome 9.** Resources are used effectively and efficiently in the provision of health and social care services.

Annex B

Definitions of Palliative Care

The World Health Organisation has produced two definitions of palliative care, in 1990[1] and in 2002.[2] There is also a WHO definition of children's palliative care.[3]

In 2015 the WHO stated:

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.

Addressing suffering involves taking care of issues beyond physical symptoms. Palliative care uses a team approach to support patients and their caregivers. This includes addressing practical needs and providing bereavement counselling. It offers a support system to help patients live as actively as possible until death

Palliative care is explicitly recognised under the human right to health. It should be provided through person-centred and integrated health services that pay special attention to the specific needs and preferences of individuals.[4]

The Scottish Government endorses this description of palliative care.

There is also a need to settle on an appropriate definition of end of life care, a term which is so often linked to palliative care. Here there is no authoritative wording which can be adopted. The following definition is recommended for use as part of the implementation of commitments within the Strategic Framework for Action.

End of life care addresses the medical, social, emotional, spiritual and accommodation needs of people thought to have less than one year to live. It includes a range of health and social services and disease specific interventions as well as palliative and hospice care for those with advanced conditions who are nearing the end of life.[5]

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[1] World Health Organisation (1990). Cancer Pain Relief and Palliative Care. WHO Technical Report Series 804. Geneva: WHO.

[2] Sepúlveda C, Marlin A, Yoshida T, Ullrich A (2002). Palliative Care: The World Health Organization's Global Perspective. *Journal of Pain and Symptom Management*, 24(2):91–96.

[3] http://www.who.int/cancer/palliative/definition/en/accessed 20 November 2015.

[4] WHO fact sheet on palliative care, Fact sheet N°402, July 2015.

[5] This definition is an adaptation of one used in a 2015 report from the National Institutes of Health in the USA. *Dying in America: Improving Quality and Honoring Individual Preferences Near the End of Life*. Committee on Approaching Death: Addressing Key End of Life Issues; Institute of Medicine. Washington (DC): National Academies Press (US); 2015.

Annex C

Palliative and End of Life Care National Advisory Group

Membership	
Professor Craig White (Chair)	Clinical Lead, Health Quality and Strategy Directorate, Scottish Government
Ms Mary Boyle	Chair, Scottish Children and Young People's Palliative Care Executive Group (SPPC)
Dr David Carroll	Clinical Lead representing North of Scotland NHS Boards
Mr Ronald Culley	Chief Officer Western Isles representing Integrated Joint Board Chief Officer Group
Dr Rosalie Dunn/ Dr Paul Baughan	Clinical Lead representing West of Scotland NHS Boards
Dr Maggie Grundy	Executive Lead NHS Education Scotland
Ms Anne Harkness	Executive Lead representing West of Scotland NHS Boards
Mr Mark Hazelwood	Chief Executive, Scottish Partnership for Palliative Care (SPPC)
Ms Kate Lennon	Hospice Chief Executive representing Independent Adult Hospices
Dr Donald Macaskill	Joint Workforce Lead, Scottish Care
Ms Elaine MacLean	Health Improvement Adviser, Care Inspectorate
Mr Peter McLoughlin	Executive Lead representing South East of Scotland NHS Boards
Ms Maria McGill	Chief Executive, Children's Hospice Association Scotland (CHAS)
Dr Euan Paterson	Royal College of General Practitioners
Ms Elaine Peace	Executive Lead representing North of Scotland NHS Boards
Mr Swaran Rakhra (until August 2015)	Membership Services Manager, Scottish Care
Dr Fran Stretton	Clinical Lead representing South of Scotland NHS Boards

Dr Sara Twaddle	Director of Evidence, Healthcare Improvement Scotland
Ms Paula McLeay/ Ms Beth Hall	Health and Social Care, Convention of Scottish Local Authorities
2 Members of the Palliative and End of Life Care Stakeholder Group	
Scottish Government	
Professor Fiona McQueen	Chief Nursing Officer
Mrs Janice Birrell	Senior Policy and Implementation Manager
Mr David Leslie (until November 2015)/ Mrs Elizabeth Gourlay	Policy Officer

Palliative and End of Life Care Stakeholder Group

Amy Dalrymple	Alzheimer Scotland - Action on Dementia
Bill Whiland	Marie Curie Expert Voices
Caroline Johnstone Koseoglu	Children's Hospice Association Scotland Parent
Catriona Forrest	University of Glasgow
Christine Johnstone	Scottish Health Council
Clare Tucker	NHS Education for Scotland (Bereavement)
Craig Stockton	Neurological Alliance of Scotland
Derek Young	AGE Scotland
Diane Rennie	Scottish Non Malignant Palliative Care Forum
Florence Burke	Carers Trust Scotland
George Beuken	Association of Hospices and Palliative Care Chaplains
Glenda M Watt	Scottish Older People's Assembly (SOPA)
Heather Noller	Carers Trust Scotland
Ian Somerville	General Medical Council Scotland
James Neil	Association of Palliative Care Social Workers
Janice Turner	NHS Education for Scotland (Bereavement)
Karen Menzies	Scottish Palliative Care Pharmacists Association
Lisa Curtice	The Health and Social Care Alliance
Marina Copping	SCYPPEx
Mark Hazelwood	Scottish Partnership for Palliative Care
Paul Wilson	Scottish Palliative Care Pharmacists Association
Pauline Britton	Scottish Partnership for Palliative Care
Rebecca Patterson	Scottish Partnership for Palliative Care
Rev Hamilton Inbadas	University of Glasgow
Richard Meade	Marie Curie

Robert Watson	Children's Hospice Association Scotland Young Adult's Council
Sandra Campbell	RCN Scotland
Sheila Mitchell	NHS Education for Scotland (Spiritual Care)
Swaran Rakhra	Scottish Care
Tanith Muller	Neurological Alliance of Scotland
Tom Berney	Scottish Older People's Assembly (SOPA)
Trisha Hatt	Macmillan Cancer Support
Victoria Carson	General Medical Council Scotland



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Any enquiries regarding this publication should be sent to us at
The Scottish Government
St Andrew's House
Edinburgh
EH1 3DG

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