

Scottish Public Health Network (ScotPHN)

**Palliative and end of life care in Scotland:
The rationale for a public health approach**

Briefing Paper 4: Policy Context

Michelle Gillies – February 2016

Briefing Paper 4. Policy context

This Briefing Paper accompanies the report ‘Palliative and end of life care: The rationale for a public health approach’. The document summarises the key policies and strategies from the last two decades that are relevant to palliative and end of life care (PELC) in Scotland. The briefing aims to provide an overview of policy direction and identify emergent themes; it does not comprehensively list all the policies and strategies that have directly or indirectly influenced PELC in Scotland. The policies and strategies discussed in this report are present in a chronological narrative without assigning a hierarchy of importance.

An overview of health strategy and policy in Scotland

Health strategy and policy in Scotland has been remarkably coherent over the last two decades. Scotland’s vision for health and social care is rooted in the evolving model of care outlined in the 2005 ‘Kerr Report’¹. Recognising that Scotland’s health needs were changing Kerr advocated a preventative anticipatory care model, delivered in communities by a fully integrated NHS, staffed by a skilled workforce and supported by information technology. Kerr argued that services should be developed with, not for, people ensuring equity of access based on need. A systematic and proactive approach to meet the needs of the most vulnerable groups, including the elderly and those with long-term conditions, was championed.

The Scottish Government’s response, ‘Delivering for Health’, set out actions to realise this vision including a performance management framework to monitor progress². Successive policies and initiatives have built upon this strategic narrative.

In 2007 ‘Better Health Better Care’ presented an outcome focused action plan to improve health, tackle inequalities and improve the quality of care through the anticipatory care and integration agendas³. A vision of a mutual NHS achieved through co-production was articulated.

‘Shifting the Balance of Care’ brought together key policy strands in a single framework⁴. The evidence base around eight priority areas, where the gains in health and wellbeing could be maximised through changing the focus of (to prevention), location of (to the community and homely settings) and responsibility for delivery of care (co-production and partnership working), was presented with practical support for implementation. It was acknowledged that health and social care systems would not have the capacity to implement all the actions identified; local communities working in partnership would have autonomy in defining and meeting their priorities.

The 2010 ‘Quality Strategy’ aligned the delivery of safe, effective, patient-centred care with governance, leadership and performance management⁵. In ‘20:20 Vision’, a vision of a Scotland in which “*everyone is able to live longer healthier lives at home or in a homely setting*” was shared⁶.

Recognising that the incremental progress that had been made was neither sufficient nor in the new political reality that followed the 2007 global economic crisis sustainable, the 2011 'Christie Report' recommended a comprehensive reform of public sector services aimed at empowering people and communities, integrating service provision, working across whole systems to increase efficiency and prioritising prevention⁷. The Scottish Government responded positively, embarking on a programme of reform supported primary legislation.

A number of themes emerge from the major strategic and policy documents published by the Scottish Government in relation to health and social care over the last two decades as outlined in Box 1.

Box 1. Major themes from health and social care strategy and policy in Scotland over the last two decades.

1. **Integration** : Horizontal within health care (community, primary and secondary care), and between health and social care and other partners including public, private and third sector through 'whole system' working; Vertical (Managed Clinical Networks)
2. **Prevention and anticipatory care**: focus on prevention, early intervention, anticipation and supported self-management; targeting root causes of inequalities
3. **Asset-based approaches**: Empowering people; building personal and community resilience; sustainability; focus on independence
4. **Co-production**: Patients as equal citizens with shared responsibilities for planning and delivering care that meets need; collaborative inter-sectoral partnership working
5. **Patient Centred**: Patients and carers as equal citizen rather than 'users' and 'providers'; delivering care according to preference and priority in a community or homely setting
6. **Patient Safety** Safe and effective services; increase reliability; reduce avoidable harm
7. **Localism**: recognition that 'one size doesn't fit all', each locality will have priorities in planning and delivering care and face opportunities and challenges meeting the needs of their population which will require local solutions developed with local communities; effective local delivery through partnership working; building community resilience
8. **Equity**: Reducing 'failure demand' though addressing stubborn inequalities in health and well-being; achieving equity of access based on need;
9. **Improvement Sciences**: Efficiency and effectiveness; 3 step improvement framework; Outcomes focused; Target driven; Benchmarking; Linked to Governance/ Accountability
10. **Governance and Accountability**: Open and transparent lines of accountability; Outcome focused; Strategic objectives which translate into national outcomes, national indicators and targets; single outcome agreements; local delivery plans;

11. **Information technology / eHealth:** Development of an eHealth record; Supporting the delivery of health and social care services and facilitating monitoring through information sharing and timely communication within and between agencies;
12. **Work force development including effective leadership:** Ensuring a skilled, flexible and competent workforce; nurturing and developing team-working and professionalism; effective leadership at every level; shared values

Palliative and end of life care strategy, policy, guidance and reports

PELC has gained increasing prominence in Scottish Government strategy and policy in recent years. Prior to the 1995 'Calman-Hine Report', palliative care had been considered almost exclusively in relation to cancer services. *Calman-Hine* recommended extension of PELC services to all those who could benefit from them⁸. In 1996 the Scottish Partnership Agency stated, "*Patients with non-malignant diseases and their carers should also be included in planning palliative care services*"⁹.

The first post-devolution government health strategy for NHS Scotland, 'Our National Health, a Plan for Action: a Plan for Change' endorsed these principles noting that whole person care should meet not just symptom control also but spiritual and social needs¹⁰. The strategy committed to developing a Managed Clinical Network for palliative care¹¹, clinical standards for palliative and specialist palliative care¹² and closer working relationships between voluntary hospices and the NHS.^{13,a}

A 2004 review of the performance of individual services against palliative care clinical standards recommended a review of specialist provision to ensure equitable access to services across Scotland¹⁴. High demand for services, a shortage of specialist staff and complex arrangements between specialist palliative care services, NHS Scotland and voluntary hospices were noted.

The PELC needs of people with non-cancer life-limiting diagnoses were increasingly being acknowledged in national strategies and policies. For example PELC was explicitly mentioned in the 2002 'Coronary Heart Disease and Stroke Strategy,'¹⁵ and the 2006 'The Future Care of Older People in Scotland'¹⁶. However a cohesive approach to achieving high quality, equitable service provision was lacking.

In 'Better Health, Better Care' the Scottish Government committed to "*the delivery of high quality palliative care to everyone in Scotland who needs it, on the basis of clinical need not diagnosis, and according to established principles of equity and personal dignity,*" although the document provided little guidance around translating this into clinical practice³.

^a NHS HDL(2003) 18 built upon commitments made in NHS Circular No. 1990(Gen)12, MEL(1993)102 and MEL(1994)104 for NHS Boards to meet 50% of the agreed running costs of voluntary of hospices providing specialist palliative care to adults and for NHS Boards and Local Authorities to jointly meet 25% of the agreed running costs of voluntary hospices providing specialist palliative care and respite to children.

In 2007 'Palliative and end of life care in Scotland: A cohesive approach,' published by the Scottish Partnership for Palliative Care made a range of recommendations to improve access to and quality of PELC including the use of assessment tools to identify people with a PELC need, integrated care pathways for delivering care (across settings and out of hours) and eHealth to improve the delivery and monitoring of services¹⁷. Further guidance was offered in 'Shifting the Balance of Care' which highlighted anticipatory care planning to avoid unnecessary transitions between care settings with changing circumstances and achieving preferred place of death at home or in a homely setting as key areas for action in relation to the PELC agenda⁴.

In 2008, Audit Scotland produced the first systematic and detailed examination of the activity, quality and costs of palliative care services across Scotland¹⁸. The report confirmed significant variation in the availability and quality of palliative care services. In response, 'Living and Dying Well: A National Action Plan for Palliative and End of Life Care in Scotland' was published which aimed to improve the quality of PELC, delivering more equitable patient-centred services for people with life-limiting illness¹⁹. The report made 24 recommendations relating to early identification and assessment of need, planning, delivery and co-ordination of services, communication, education and workforce development. A number of short life working groups were established to make further recommendations around specific actions. NHS boards were required to produce delivery plans against the actions required. These actions were reiterated but not developed further, in the 2008 'Better Cancer Care, An Action Plan'²⁰.

The Public Audit Committee published its finding on the 2008 Audit Scotland report the following year, welcoming the national strategy but making further recommendations around national data collection, the need for robust commissioning arrangements for services and the need for a national Do Not Attempt Cardiopulmonary Resuscitation policy²¹. These points were addressed in the Scottish Governments response²² and two subsequent reports from 2011²³ and 2012²⁴ that outlined the considerable progress made against the key actions from Living and Dying Well.

The most significant developments arising from or related to Living and Dying Well include:

Leadership and Clinical Governance

- Development of a National Advisory Group
- Appointment of NHS National Clinical lead for PELC
- Appointment of National Clinical Lead for Palliative eHealth
- Appointment of Executive Leads for PELC at NHS board level
- Development of a Scottish Children's and Young Peoples Palliative Care Executive

Strategy and Policy

- Publication and implementation of the NHSScotland Do Not Attempt Cardiopulmonary Resuscitation (DNACPR) Integrated Adult Policy²⁵
- Publication and implementation of NHSScotland Do Not Attempt Cardiopulmonary Resuscitation (DNACPR) Policy for Children and Young People²⁶

- Publication of Shaping Bereavement Care leading to 'Bereavement Care: A Framework for Action for Bereavement Care in NHSScotland'²⁷
- Development of 'A Framework for Delivery of Palliative and End of Life Care for Children and Young People'²⁸
- PELC referenced in strategies for dementia (Scotland's National Dementia Strategy²⁹), care for older people (Reshaping Care for Older People³⁰) and long term conditions (Long Term Conditions Collaborative³¹)
- 'Caring Together: The Carers Strategy for Scotland'³² published in 2011 to support implementation of recommendations from 'Care 21: The Future of Unpaid Care in Scotland'³³ long which recognised the invaluable role of carers and a need to support them.

Clinical Standards and Quality Improvement

- Development of national indicators for PELC published by NHS Health Improvement Scotland in 2013 examining four domains including identification, assessment and care planning, accessing patient information and place of death³⁴
- Development and roll out of the Scottish Palliative Care Guidelines in 2013 which reflect a consensus of opinion about good practice in the management of adults with life limiting illness³⁵
- Health Quality Strategy level one outcome measure relating to percentage of last 6 months of life spent in a home or community setting³⁶
- NHS Health Improvement Scotland produced a DNACPR indicator in 2013³⁷
- Inclusion of palliative care measures and criteria in disease specific clinical standards for neurological health services³⁸, heart disease³⁹ and chronic obstructive pulmonary disease⁴⁰

Service Design and Delivery

- Guidance on the commissioning of hospice services, 'Better Palliative and End of Life Care: Creating a New Relationship Between Independent Adult Hospices and the NHS Boards in Scotland'⁴¹
- Development and implementation of the Palliative Care Direct Enhanced Services (DES)⁴²
- Roll out of the electronic palliative care summary (ePCS) to facilitate timely communication at transitions of care

Education and workforce development

- Establishment of Palliative and end of life care education champion at board level
- Development of a range resources by NHS Education Scotland to provide practical support to health and social care providers including the DNACPR STAR module, an Advance and Anticipatory Care Planning Toolkit and a Palliative Care Formulary for prescribers⁴³

Wider Society

- Development of Good Life, Good Death, Good Grief, an assets-based approach to promoting openness around death, dying and bereavement by SPPC at the request of the Scottish Government⁴⁴

However, the 2012 progress report identified specific challenges still to be met, including the need for a cultural shift to foster openness about death, dying and loss, embedding new tools to identify and assess need in clinical practice and investment in cross-sector infrastructure to enable timely communication and ensure collaborative working and co-ordination of care²³. The report also noted the difficulty of making statements on progress in the absence of data on outcomes, and in many cases data on activity.

In 2013 an inquiry was established to review the use of the Liverpool Care Pathway (LCP) in England following media criticism and reports of poor patient care relating to its use⁴⁵. Use of the tool, developed in hospices as an approach to end of life care, had been advocated in PELC strategies across the devolved nations. It is noteworthy that despite being embedded in clinical practice for over 10 years the pathway had never been prospectively evaluated. The inquiry found examples where implementation of the pathway had improved patient care, but also examples where the pathway had become a ‘tick-box’ exercise, a generic protocol that replaced compassionate care with little or no regard for individual patients needs associated with poor communication between professionals and carers. The findings of the inquiry highlight the difficulties in ‘up-scaling’ and implementing an intervention developed for one care setting (hospice) for use in another care setting (acute hospital). The inquiry recommended withdrawal of the LCP. A number of observations were made, including a lack of carer involvement in care, poor communication by professionals, a lack of compassion, skills and competence in caring for the dying and the need for a national conversation about death, dying and loss. In concluding the report entitled ‘More Care Less Pathway’ noted that a *“system-wide approach to professional practice and institution provision, measurable and monitored, is required to bring about improvements in care for the dying. A strategic approach needs to be taken to the problem – a coalition of regulatory and profession”*⁴⁵. In June 2015 the Access to Palliative Care Bill [HL] 2-15-16 was introduced to the UK parliament⁴⁶.

In Scotland, a subgroup of the National Advisory Group was established to consider the findings of ‘More Care Less Pathway’. Included in a suite of recommendations to the Scottish Government was a recommendation to phase out the LCP. In 2014 national guidance on ‘Caring for People in the last few days and hours of life’ was published by the Scottish Government which outlined the principles of providing high quality, patient-centred care applicable in all care settings⁴⁷.

The ethos of PELC was present in ‘20:20 Vision’s’ outline of holistic care but death, dying, and loss, were not explicitly mentioned⁶. This is an important omission. There is a need for high-level acknowledgement that death, dying and loss are inevitable human experiences. Through policy and practice the avoidable harms associated with death, dying and loss can be mitigated, but death cannot be prevented. It should also be considered that, for some people, hospital may be the most appropriate care setting to meet their needs. Aggressive pursuit of policy that sites care in the community risks creating a culture in which hospitalisation is considered a failure of health and social

care. It is important that professional and patients feel empowered to make clinical decisions based on need, safety and choice, not policy ambition.

Palliative care emerged as an important theme in scrutiny of the Assisted Suicide (Scotland) Bill which was defeated following stage 1 Parliamentary debate on 27 May 2015⁴⁸. In July 2015 the Scottish Parliament's Health and Sport Committee launched a Parliamentary Inquiry into palliative care in Scotland with a remit to examine access to palliative care, communication around palliative care and international metrics used in palliative care. The Committee published its findings on 25 November 2015⁴⁹. Among the 63 comments and recommendations, the report highlighted inequities in access to PELC and the specific needs of babies, children and young people. Confusion over the definition of PELC was noted with a request for the Scottish Government to provide clear definitions of palliative care and end of life care in its forthcoming 'Strategic Framework for Action on Palliative and End of Life Care'. An *"information deficit"* relating to the provision of, access to and outcomes from PELC services was identified. The importance of electronic information sharing and anticipatory care planning was noted and the need for education, training and workforce development to support professionals deliver high quality, person-centred care recognised. The Committee identified a need to enable people to have private and public conversations around death, dying and loss and sought assurance from the Scottish Government that it would use the 'Strategic Framework for Action on Palliative and End of Life Care' to support this. The Committee *"recognize[d] 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"*⁴⁹.

Concurrent with the Parliamentary Inquiry, PELC provision and care for the frail and elderly in the out of hours (OOH) period were considered in a national review of OOH primary care provision in Scotland led by Sir Lewis Ritchie that reported on 30 November 2015⁵⁰. The report made 28 recommendations on the provision of OOH primary care, including proposing a new model for OOH and urgent care. The review acknowledged the need for people at the end of life and their carers to be able to directly access care and assistance through a local 24/7 helpline without going through NHS24. The need for safe and secure electronic information sharing across care settings and the importance of anticipatory care planning were highlighted. The review advocated the development of local PELC pathways to ensure that people with a PELC need, their carers and the professionals providing care, know how to access resources; the role of community nursing support, allied health professionals and third and independent sectors organisations in providing care and support in the OOH period was noted. Recommendations to support the delivery of care in non-acute setting, at home, in hospices and care home, were made.

On 18 December 2015, as this report was in final preparation for publication, the Scottish Government published their 'Strategic Framework for Action on Palliative and End of Life Care' (SFA)⁵¹. The SFA set out a vision of everyone in Scotland who needs it having access to PELC by 2021. Specific aims and objectives to ensure PELC needs

are identified, access to PELC is equitable and to enable people, professionals, communities, statutory and non-statutory organisations to develop and use the assets available to them to better deal with death, dying and loss were articulated. The SFA identified a need for robust systems to measure and monitor activity and outcomes, and a co-ordinated approach to research and knowledge exchange to capitalise on Scotland's wealth of clinical and academic expertise and build the evidence base around what works, for whom and why. Encouragingly the SFA acknowledged the importance of adopting a public health approach to PELC and the contribution that the public health workforce could make to the PELC agenda. The Scottish Government committed 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.

The national implementation group will be established to support the develop of local improvement plans, oversee the development of an educational framework, support capacity building and establish mechanisms for shared learning, with progress in improving care and achieving outcomes documented in a national annual learning and improvement report. Additional funding of £3.5 million over four years will support implementation.

References

1. Building a health service fit for the future: a national framework for service change in the NHS in Scotland ('The Kerr Report'). Scottish Executive, Edinburgh. 2005. Accessed on 21/9/15 at <http://www.scotland.gov.uk/Publications/2005/05/23141307/13104>
2. Delivering for Health. Scottish Executive, Edinburgh. 2005. Accessed on 21/9/15 at <http://www.scotland.gov.uk/Publications/2005/11/02102635/26356>
3. Better Health, Better Care: Action Plan. The Scottish Government, Edinburgh. 2007. Accessed on 21/9/15 at <http://scotland.gov.uk/Publications/2007/12/11103453/9>
4. Improving Outcomes by Shifting the Balance of Care: Improvement Framework. Shifting the Balance of Care Delivery Group. The Scottish Government, Edinburgh. 2009. Accessed on 21/9/15 at <http://www.shiftingthebalance.scot.nhs.uk/improvement-framework/>
5. The Healthcare Quality Strategy for NHSScotland. The Scottish Government, Edinburgh. 2010. Accessed on 21/9/15 at <http://www.scotland.gov.uk/Publications/2010/05/10102307/0>
6. A Route Map to the 2020 Vision for Health and Social Care. The Scottish Government, Edinburgh. 2011. Accessed on 21/9/15 at <http://www.gov.scot/Topics/Health/Policy/2020-Vision>
7. The Christie Commission of the Future Delivery of Public Services. June 2011. Accessed on 21/9/15 at <http://www.gov.scot/resource/doc/352649/0118638.pdf>
8. The Calman Hine Report. A policy framework for commissioning cancer services: A report by the Expert Advisory Group on cancer to the Chief Medical Officers of England and Wales. 1995. Accessed on 21/9/15 at http://webarchive.nationalarchives.gov.uk/20080814090336/dh.gov.uk/en/Publicationsandstatistics/Publications/PublicationsPolicyAndGuidance/DH_4071083
9. Palliative Cancer Care: The Integration of Palliative Care with Cancer Services. Scottish Partnership Agency for Palliative and cancer Care. Accessed on 21/9/15 at <http://www.palliativecarescotland.org.uk/content/publications/PalliativeCancerCareTheIntegrationofPalliativeCarewithCancerServices.pdf>
10. Our National Health, a Plan for Action, a Plan for Change. The Scottish Executive, Edinburgh. 2006. Accessed on 21/9/15 at <http://www.gov.scot/Publications/2000/12/7770/File-1>
11. A framework for the operation of managed clinical networks in palliative care. The Scottish Partnership Agency for Palliative Care. February 2000. Accessed on 21/9/15: <http://www.palliativecarescotland.org.uk/content/publications/AframeworkfortheoperationofMANAGEDCLINICAL-NETWORKSINPALLIATIVECARE.pdf>
12. Clinical Standards Specialist Palliative Care. Clinical Standards Board for Scotland. 2002. Accessed on 21/9/15 at http://www.healthcareimprovementscotland.org/previous_resources/standards/specialist_palliative_care.aspx

13. NHS HLD(2003)18. Funding of Specialist Palliative Care provided by independent voluntary hospices in Scotland. The Scottish Executive Health Department, Edinburgh. 2003. Accessed on 21/9/15 at http://www.sehd.scot.nhs.uk/mels/HDL2003_18.pdf
14. National Overview: Specialist Palliative Care. NHS Quality Improvement Scotland. 2004.
15. Coronary Heart Disease and Stroke: Strategy for Scotland. The Scottish Executive. 2002. Accessed on 21/9/15 at <http://www.gov.scot/Resource/Doc/46997/0013955.pdf>
16. Range and Capacity Review Group: Second Report: The Future Care of Older People in Scotland. The Scottish Executive, Edinburgh. 2006. Accessed on 21/9/15 at <http://www.gov.scot/Publications/2006/04/25111735/22>
17. Palliative and end of life care in Scotland: the case for a cohesive approach. Scottish Partnership for Palliative Care. 2007. Accessed on 21/9/15 at http://www.palliativecarescotland.org.uk/content/publications/Palliative_and_End_of_Life_Care_in_Scotland.pdf
18. Review of Palliative Care Services in Scotland. Audit Scotland, Edinburgh. 2008. Accessed on 21/9/15 at http://www.audit-scotland.gov.uk/docs/health/2008/nr_080821_palliative_care.pdf
19. Living and Dying Well: A national action plan for palliative and end of life care in Scotland. Scottish Government, Edinburgh. 2008. Accessed on 21/9/15 at <http://www.gov.scot/Resource/Doc/239823/0066155.pdf>
20. Better Cancer Care, An Action Plan. The Scottish Government, Edinburgh. 2008 Accessed online on 21/9/15 at <http://www.gov.scot/Resource/Doc/242498/0067458.pdf>
21. Public Audit Committee Report. 1st Report 2009 (session 3). The Scottish Parliament, Edinburgh. 2009. Accessed on 21/9/15 at <http://archive.scottish.parliament.uk/s3/committees/publicAudit/reports-09/paur09-01.htm>
22. Public Audit Committee Report. Papers: 6th Meeting, 25 March 2009. The Scottish Parliament, Edinburgh. 2009. Accessed on 21/9/15 at <http://archive.scottish.parliament.uk/s3/committees/publicAudit/papers-09/paup09-06.pdf>
23. Living and Dying Well: Building on Progress. Scottish government, Edinburgh. 2011. Accessed on 21/9/15 at <http://www.gov.scot/Publications/2011/01/27090834/0>
24. Living and Dying Well: Update on Progress. Scottish Government, Edinburgh. 2012. Accessed on 21/9/15 at <http://www.gov.scot/Topics/Health/Quality-Improvement-Performance/PELC/ProgressReport>
25. NHSScotland DNACPR Policy. The Scottish Government, Edinburgh. 2010. Accessed on 21/9/15 at <http://www.gov.scot/Publications/2010/05/24095633/0>
26. NHSScotland CYPADM Policy Document. The Scottish Government, Edinburgh. 2012. Accessed on 21/9/15 at <http://www.gov.scot/Topics/Health/Quality-Improvement-Performance/peolc/DNACPR/CYPADMPolicydocument>

27. Bereavement Care: A Framework for Action for bereavement Care in NHSScotland. The Scottish Government, Edinburgh. 2011. Accessed on 21/9/15 at http://www.sehd.scot.nhs.uk/mels/CEL2011_09.pdf
28. A Framework for Delivery of Palliative and End of Life Care for Children and Young People. The Scottish Government, Edinburgh. 2012. Accessed on 21/9/15 at <http://www.cen.scot.nhs.uk/files/FrameworkDeliveryPalliativeCareChildrenYoungPeopleScotland.pdf>
29. Scotland's National Dementia Strategy. The Scottish Government, Edinburgh. 2013. Accessed on 21/9/15 at <http://www.gov.scot/Topics/Health/Services/Mental-Health/Dementia/DementiaStrategy1316>
30. The Reshaping care for older people: A programme for change 2011-2021. The Scottish Government, Edinburgh. 2012. Accessed on 21/9/15 at <http://www.gov.scot/Topics/Health/Support-Social-Care/Support/Older-People/Reshaping-Care>
31. Long term conditions collaborative: Improving complex care. The Scottish Government, Edinburgh. 2009. Accessed on 21/9/15 at <http://www.gov.scot/resource/doc/263175/0078713.pdf>
32. "Caring together" The carers' strategy for Scotland 2010 – 2015. The Scottish Government, Edinburgh. 2010. Accessed on 21/9/15 at <http://www.gov.scot/Publications/2010/07/23153304/0>
33. Care 21: The Future of Unpaid Care in Scotland. The Scottish Government, Edinburgh. 2006. Accessed on 21/9/15 at <http://www.gov.scot/Publications/2006/02/28094157/0>
34. Palliative and end of life care indicators. Health Improvement Scotland. 2013. Accessed on 21/9/15 at http://www.healthcareimprovementscotland.org/our_work/person-centred_care/palliative_care/palliative_care_indicators.aspx
35. Scottish Palliative Care Guidelines. Health Improvement Scotland. 2013. Accessed on 21/9/15 at <http://www.palliativecareguidelines.scot.nhs.uk>
36. Quality Outcome Measure 10: Percentage of last 6 months of life spent at home or in a community setting. Information Services Division. 25 August 2015. Accessed on 21/9/15 at <http://www.isdscotland.org/Health-Topics/Health-and-Social-Community-Care/Publications/>
37. DNACPR Indicator. Health Improvement Scotland. 2013. Accessed on 21/9/15 at http://www.healthcareimprovementscotland.org/our_work/person-centred_care/dnacpr/dnacpr_indicator.aspx
38. Neurological Health Services Clinical Standards. Health Improvement Scotland. 2009. Accessed on 21/9/15 at http://www.healthcareimprovementscotland.org/our_work/long_term_conditions/neurological_health_services/neurological_standards_2009.aspx
39. Clinical standards for Heart Disease. Health Improvement Scotland. 2010. Accessed on 21/9/15 at http://www.healthcareimprovementscotland.org/our_work/cardiovascular_disease/heart_disease_services/heart_disease_standards.aspx

40. Chronic Obstructive Pulmonary Disease (COPD) Service – clinical standards and evaluation. Health Improvement Scotland. 2010. Accessed on 21/9/15 at http://www.healthcareimprovementscotland.org/our_work/long_term_conditions/copd_implementation/copd_clinical_standards.aspx
41. A Partnership for Better Palliative and End of Life Care: Creating a New Relationship Between Independent Adult Hospices and the NHS Boards in Scotland. The Scottish Government, Edinburgh. 2010. Accessed on 21/9/15 at <http://www.gov.scot/resource/doc/924/0111432.pdf>
42. NHS Circular PCA(M)(2012)6. The primary medical services directed enhanced services (Scotland) 2012. The Scottish Government, Edinburgh. Accessed on 21/9/15 at [http://www.sehd.scot.nhs.uk/pca/PCA2012\(M\)06.pdf](http://www.sehd.scot.nhs.uk/pca/PCA2012(M)06.pdf)
43. NHS Education for Scotland. Palliative care in practice. Accessed on 21/9/15 at <http://www.palliativecareinpractice.nes.scot.nhs.uk>
44. Good Life, Good Death, Good Grief. Accessed on 21/9/15 at <http://www.goodlifedeathgrief.org.uk>
45. Neuberger, J., Guthrie, C., Aaronovitch, D., *et al.* More Care, Less Pathway. A review of the Liverpool Care Pathway. 2013. Accessed on 21/9/15 at https://www.gov.uk/government/uploads/system/uploads/attachment_data/file/212450/Liverpool_Care_Pathway.pdf
46. Access to Palliative Care Bill [HL] 2-15-16 . UK Parliament. 2015. Accessed on 21/9/15 at <http://services.parliament.uk/bills/2015-16/accesstopalliativecare.html>
47. Caring for People in the last few days and hours of life. The Scottish Government, Edinburgh. 2014. Accessed on 21/9/15 at <http://www.gov.scot/Resource/0046/00466779.pdf>
48. Assisted Suicide (Scotland) Bill Policy Memorandum. Accessed on 31/1/16 at http://www.scottish.parliament.uk/S4_Bills/Assisted%20Suicide/b40s4-intro-dp.pdf
49. We need to talk about Palliative Care. A Parliamentary Inquiry into Palliative Care in Scotland by the Health and Sports Committee. Accessed on 13/01/16 at http://www.scottish.parliament.uk/S4_HealthandSportCommittee/Reports/HSS042015R15.pdf
50. Pulling together: transforming urgent care for the people of Scotland. The Report of the Independent Review of Primary Care Out of Hours Services. The Scottish Government. The Scottish Government, Edinburgh. November 2015. Accessed on 13/01/16 at <http://www.gov.scot/Resource/0049/00490526.pdf>
51. A Strategic Framework for Action on Palliative and End of Life Care. The Scottish Government, Edinburgh. December 2015. Accessed on 13/01/16 at <http://www.gov.scot/Resource/0049/00491388.pdf>



ScotPHN r e p o r t

For further information contact:

ScotPHN

c/o NHS Health Scotland

Meridian Court

5 Cadogan Street

Glasgow

G2 6QE

Email: nhs.healthscotland-scotphn@nhs.net

Web: www.scotphn.net

Twitter: [@NHS_ScotPHN](https://twitter.com/NHS_ScotPHN)