



# **Scottish Atlas of Palliative Care**

Hamilton Inbadas

Michelle Gillies

David Clark





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September 2016



**Authors**

The Rev Dr Hamilton Inbadas - Research Associate, School of Interdisciplinary Studies, University of Glasgow, Dumfries Campus

Dr Michelle Gillies - Clinical Lecturer (Public Health), Institute of Health and Wellbeing, University of Glasgow

Professor David Clark - Wellcome Trust Investigator, School of Interdisciplinary Studies, University of Glasgow, Dumfries Campus

**Editorial office**

Glasgow End of Life Studies Group  
The University of Glasgow, Dumfries Campus  
Rutherford/McCowan Building  
Crichton University Campus  
Dumfries DG1 4ZL  
Scotland

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Amanda Jane Ward assisted with data collection in the survey of specialist palliative care services. Rachel Lucas provided data collation and information for the socio economic data summary. Scott Murray contributed material for the section on education. Mark Hazelwood assisted with the sections on palliative care development and policy, and made general comments throughout an earlier draft. Barry Melia assisted with the section on opioids. Lauren Parry provided the GIS data mapping expertise and Andrew Rees helped with design issues for the data maps. Any mistakes or omissions are those of the authors alone.



# Introduction









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There is significant interest in Scotland in how better to describe, assess and improve the various forms of palliative care that are delivered in different settings. One aspect of this involves continuing to review the development of specialist palliative care provision along with the efforts that are taking place to make palliative care available more widely, to all who can benefit from it.

The European Association for Palliative Care (EAPC) has produced two Atlases of Palliative Care (2007, 2013) which set out some of these details for the 53 countries of the World Health Organisation European Region. The European Atlases contain entries for the United Kingdom and have proved useful in providing high level summaries of information that can be monitored over time.

During 2015, as work proceeded on the Scottish Parliament inquiry into palliative care and the *Scottish Government's Strategic Framework for Action on Palliative and End of Life Care*, the idea was proposed that, using the EAPC template as a guide, we might produce an extended 'atlas entry' for Scotland. This document is the result. It is a contribution to Commitment 9 in the *Strategic Framework*, which refers to 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.

The quantitative data presented here on specialist palliative care services in Scotland is based on an adapted version of the questionnaire survey used for the production of the European Atlas. Between August and September 2015 the

questionnaire was emailed to the Chief Executive Officers of each of the independent hospices in Scotland and to the Executive Leads for Palliative Care for each National Health Service Board and, where available, the Chairperson of the palliative and end of life care Managed Clinical Network for each Board. These individuals were asked to identify a person from their organisation who would be available to discuss their responses to the questionnaire in a telephone interview with one of three interviewers (MG, AJW, HI). Some informants (n=3) filled in the questionnaire online directly. The survey was undertaken in collaboration with the Scottish Public Health Network, as it prepared its 2015 report on palliative care.

On this basis, the current document contains up to date information on the levels and character of specialist palliative care in Scotland. It also provides wider summaries of palliative care development in Scotland over time, using the 2006 benchmark of the first EAPC Atlas as a point of departure. The document also contains extensive details of available publications, reports, policy statements and guidelines relating to palliative and end of life care in Scotland.

We believe this 'Atlas' is a rich resource for those seeking an overview of the development and current organisation of palliative care in Scotland. Inevitably, it is a 'work in progress' and suggestions on its utility, format and options for improvement would be gratefully received.

**Hamilton Inbadas, Michelle Gillies, David Clark  
September 2016**



# 01. Socio-economic data Scotland

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## SOCIO-ECONOMIC DATA

> **Population** 2014  
5,347,600

---

> **Density** 2014  
69 per km<sup>2</sup>

---

> **Surface**  
77,925 km<sup>2</sup>

---

> **Gross Domestic Product per capita** 2015  
£ 28,500

---

> **Physicians per 1,000 inhabitants**  
0.8

---

> **Health expenditure per capita** 2013-14  
£ 2029

---

> **Health expenditure, total [% of Gross]** 2013-14  
17.3

---

> **Human Development Index 2014 [UK]**  
0.907

---

> **Human Development Index Ranking Position [UK]** 2004  
14

---



## 02. Health boards in Scotland and population

**SHETLAND**  
23210







# Definitions







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In preparing this document the following definitions have been used, chiefly drawn from those of the European Association for Palliative Care and the European Atlas of Palliative Care.

Specialist palliative care services are health care facilities and programmes established for the delivery of palliative care through medical, nursing and allied health professionals with specialist qualification and/or training in palliative care.

The following definitions were used to describe the variety of specialist palliative care services available in Scotland:

**Inpatient units** refer to specialist in-patient facilities with beds available or allocated for palliative care patients. These can be in hospitals, hospices or nursing homes.

**Out-patient clinics** refer to services where consultation and treatment are delivered to patients who visit a specialised palliative care clinic based in a hospital or hospice on an out-patient basis.

**Hospital support teams** refer to professional teams that provide specialist palliative care advice and support to other clinical staff, patients and their families and carers in the hospital environment. They offer formal and informal education, and liaise with other services in and out of the hospital. Hospital palliative care support teams, in the first instance, offer support to healthcare professionals in hospital units and other settings not specialised in palliative care.

**Home care teams** refer to specialised palliative care teams that deliver care to patients who need it at home and support to their families and carers at the patient's home. They also provide specialist advice to general practitioners, family doctors and nurses caring for the patient at home.

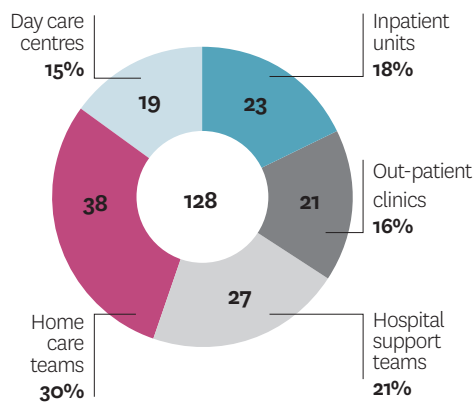
**Day care centres** refer to spaces in hospitals, hospices, palliative care units or the community especially designed to promote recreational and therapeutic activities among patients who can benefit for this type of palliative care.



## 03. Specialist palliative care services in Scotland

### PALLIATIVE CARE SERVICES [2015]

SERVICE	NO	%
Inpatient units	23	18
Out-patient clinics	21	16
Hospital support teams	27	21
Home care teams	38	30
Day care centres	19	15
TOTAL	128	100

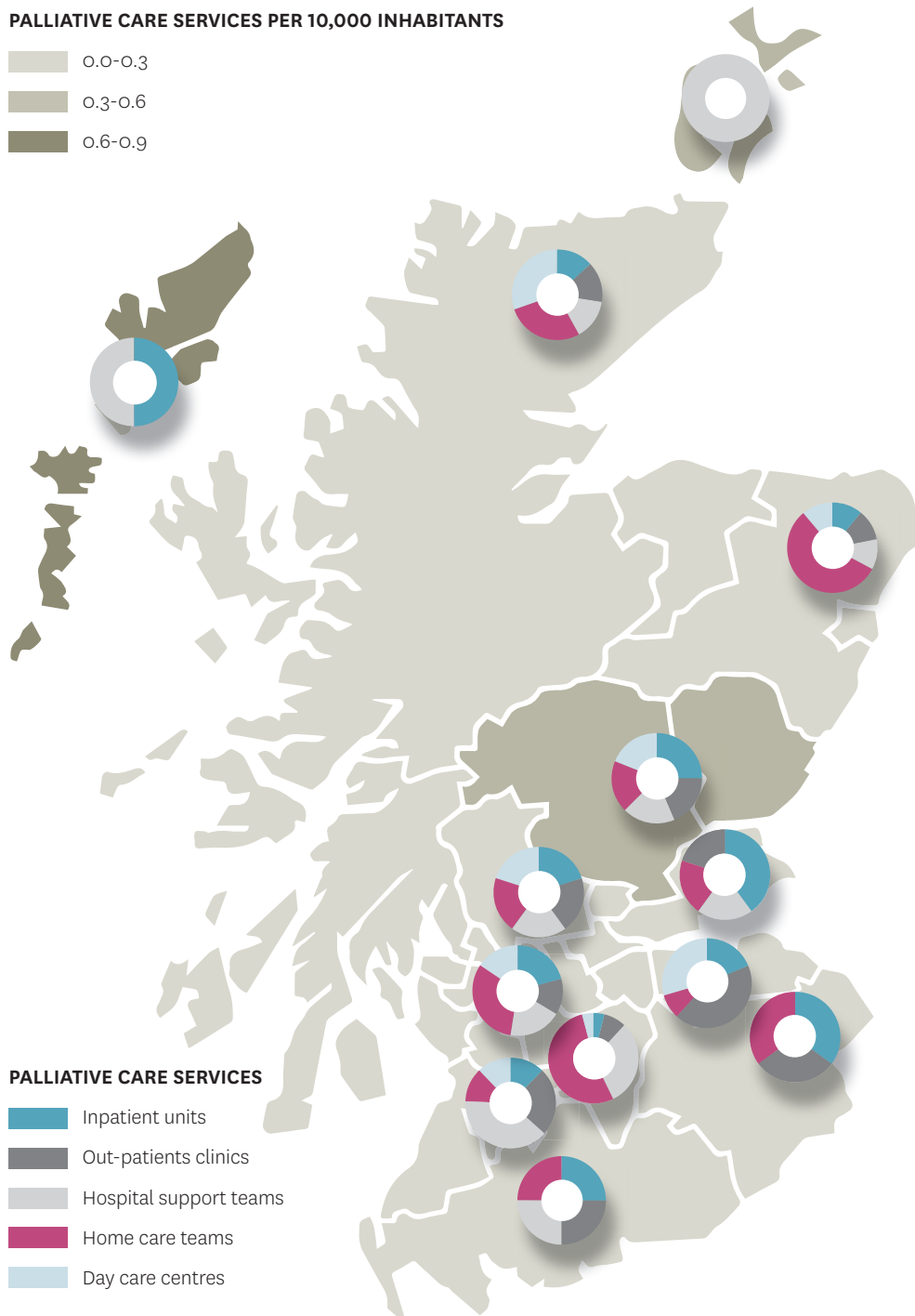


In addition to the numbers of services indicated above, Marie Curie Scotland, Macmillan Cancer Support and Children's Hospice Association Scotland (CHAS) provide palliative care services at the national level, often in collaboration with other palliative care services.

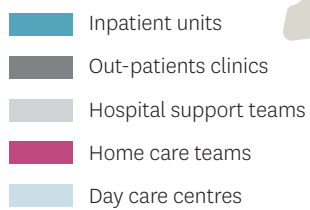




**PALLIATIVE CARE SERVICES PER 10,000 INHABITANTS**

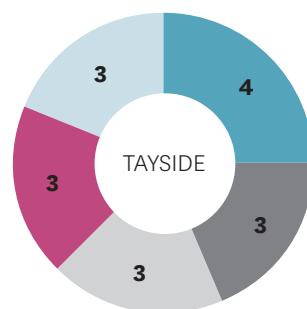
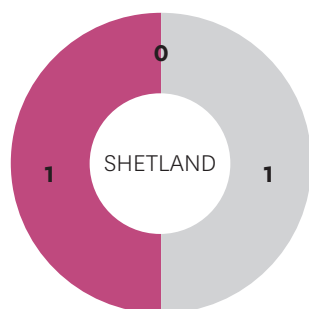
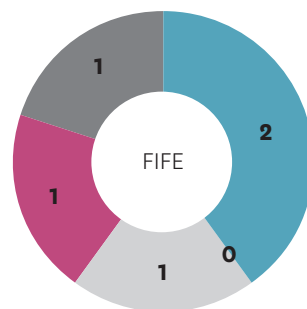
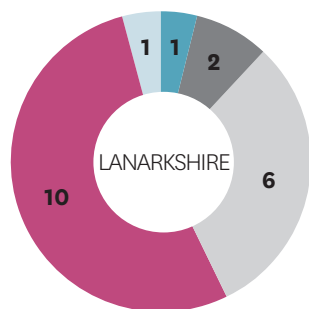
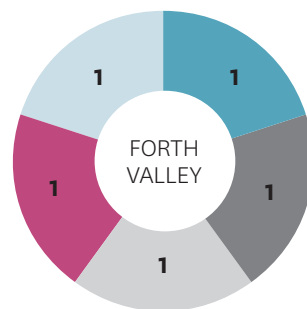
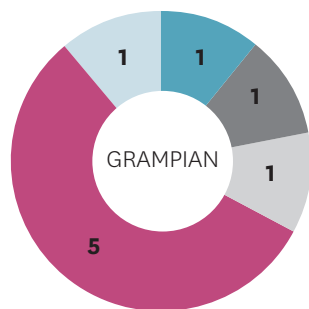
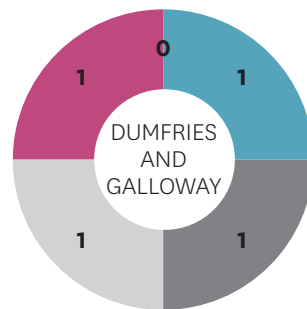
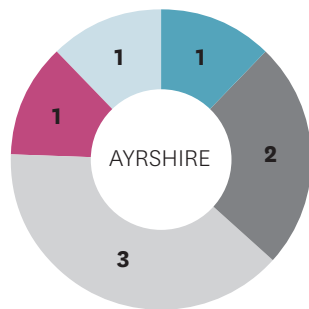


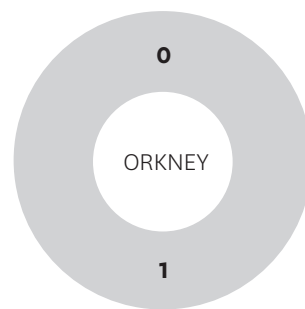
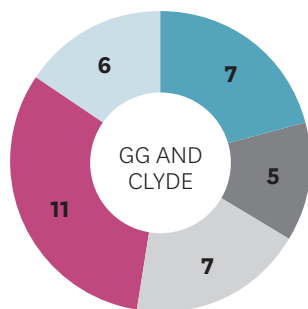
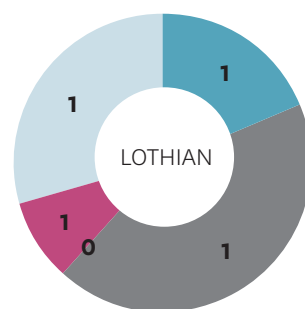
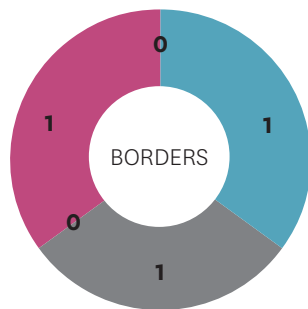
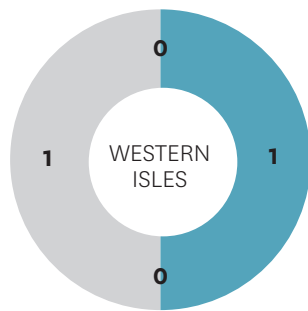
**PALLIATIVE CARE SERVICES**





## 04. Specialist palliative care services per health board



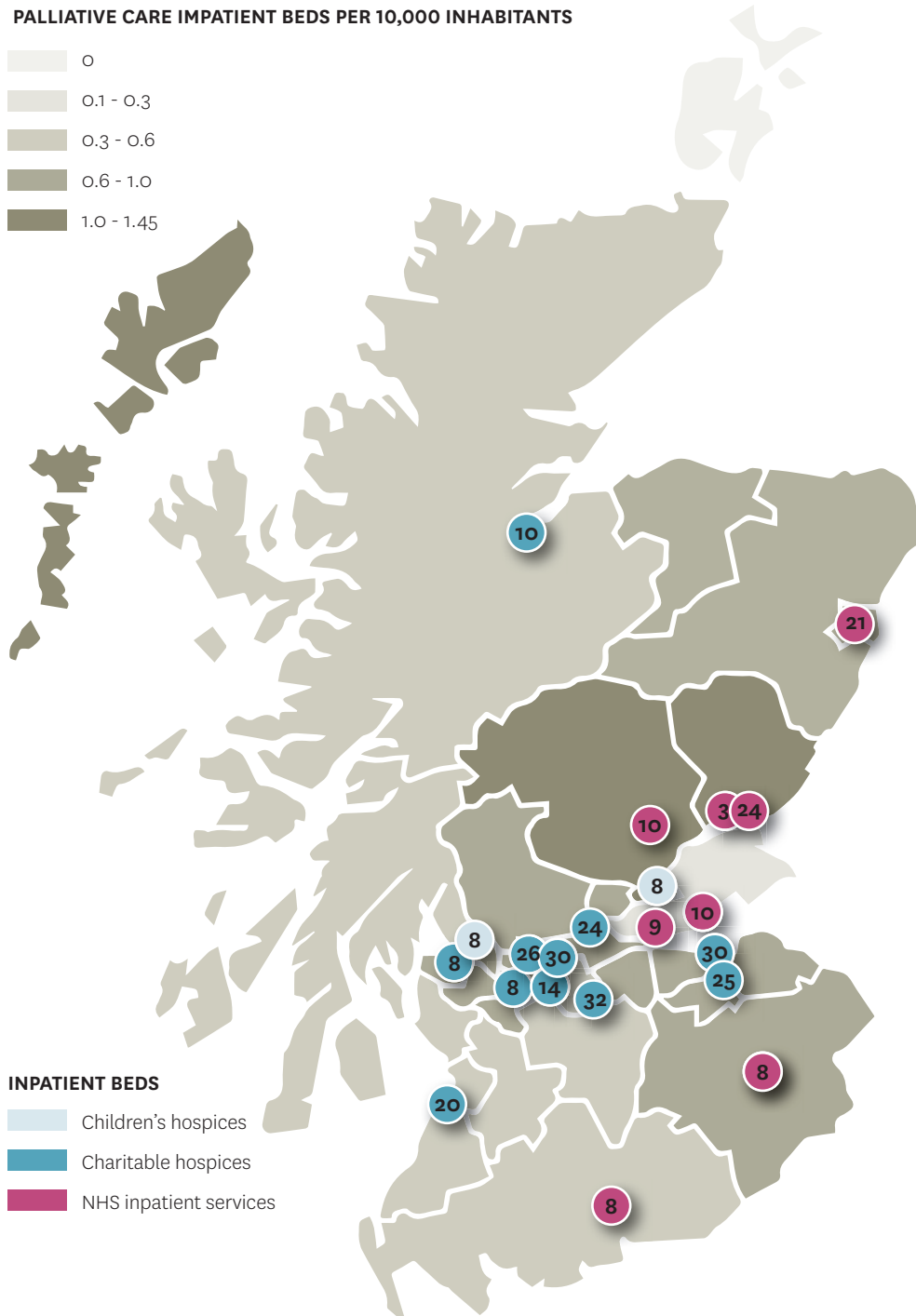
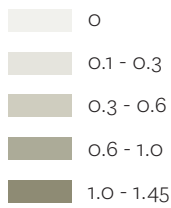


- Inpatient units
- Out-patients clinics
- Hospital support teams
- Home care teams
- Day care centres

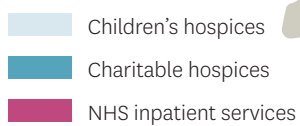


# 05. Palliative care inpatient beds in Scotland

PALLIATIVE CARE IMPATIENT BEDS PER 10,000 INHABITANTS



INPATIENT BEDS

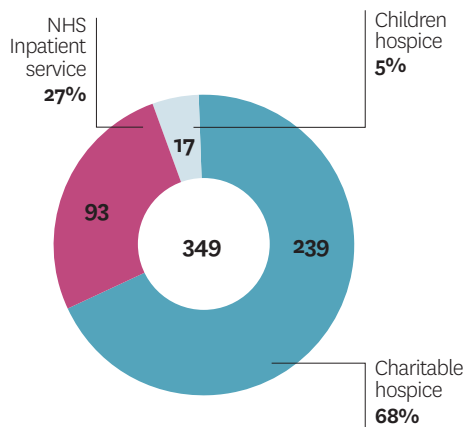




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### PALLIATIVE CARE INPATIENT BEDS [2015]

NHS Inpatient services	93
Charitable hospices	239
Children's hospices	17
<b>TOTAL</b>	<b>349</b>



<b>Palliative care beds (ratio per million inhabitants)</b>	349 (65.3 per million inhabitants)
<b>Palliative care for children</b>	A significant number of all kinds of resources; 2 inpatient hospices and hospice at home by Children's Hospice Association Scotland





# Paliative Care development indices









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### KEY DATA ON PALLIATIVE CARE DEVELOPMENT

Legislation on PC	Yes <input checked="" type="checkbox"/> No <input type="checkbox"/>
Official National Strategy	Yes <input checked="" type="checkbox"/> No <input type="checkbox"/>
National Association	Yes <input checked="" type="checkbox"/> No <input type="checkbox"/>
National Conference	Yes <input checked="" type="checkbox"/> No <input type="checkbox"/>
Scientific Journal	Yes <input type="checkbox"/> No <input checked="" type="checkbox"/>
Research Centres	Yes <input checked="" type="checkbox"/> No <input type="checkbox"/>
World PC Day initiatives	Yes <input checked="" type="checkbox"/> No <input type="checkbox"/>
Participants at EAPC Conference 42 delegates from Scotland in 2015	Yes <input checked="" type="checkbox"/> No <input type="checkbox"/>
Status of Palliative Medicine	Full specialty

### WORLDWIDE PALLIATIVE CARE ALLIANCE LEVEL OF DEVELOPMENT: 4B

Based on the Worldwide Palliative Care Alliance six part grading of palliative care development, Scotland – as part of the United Kingdom – would be placed in the highest category – 4b Advanced integration. This grading is explained in full in: Lynch, T., Connor, S., and Clark, D. (2013) Mapping levels of palliative care development: a global update. *Journal of Pain and Symptom Management* 45(6): 1094-1106.



## 06. Hospice and palliative care milestones up to 2006

- 
- 1950** St Margaret's Hospice opened in Clydebank by the Religious Sisters of Charity
- 
- 1977** St Columba's Hospice, Edinburgh opens as first independent charitable hospice in Scotland
- 
- 1991** Formation of the Scottish Partnership for Palliative Care - <http://www.palliativecarescotland.org.uk/>
- 
- 1992** Formation of Children's Hospice Association of Scotland (CHAS) - [http://www.chas.org.uk/assets/0001/6315/DIG\\_-\\_4\\_Background\\_Information\\_FINAL.doc](http://www.chas.org.uk/assets/0001/6315/DIG_-_4_Background_Information_FINAL.doc)
- 
- 2000** *Our National Health: A plan for action, a plan for change* – The Scottish Executive Health Department (SEHD) states that good palliative care must be available to all those who need it regardless of diagnosis - <http://www.gov.scot/Publications/2000/12/7770/File-1>
- 
- 2001** *Cancer in Scotland: Action for change (2001)* - Outlines the important role palliative care plays in cancer care while acknowledging the wider application of palliative care to non-cancer conditions. It states that all NHS Boards should undertake comprehensive needs assessments for palliative care, including the need for joint working across care sectors and agencies - <http://www.gov.scot/Publications/2001/07/9490/File-1>
- 
- 2002** *Coronary Heart Disease and Stroke: Strategy for Scotland* - outlines that palliative care services should be open to everyone with end stage heart failure - <http://www.gov.scot/Publications/2002/10/15530/11595>
- 
- 2006** *Joined up Thinking, Joined up Care: Increasing access to Palliative Care for People with Life-threatening conditions other than cancer.* Scottish Partnership for Palliative Care - <https://www.palliativecarescotland.org.uk/content/publications/2006-11-Joined-up-thinking-Joined-up-care-Full-Report.pdf>



## 07. Developments in hospice and palliative care since 2006

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### MOST SIGNIFICANT CHANGES IN HOSPICE AND PALLIATIVE CARE

Two government strategic documents have been published in this period.

***Living and Dying Well*** (2008) - <http://www.gov.scot/Publications/2008/10/01091608/0>

***Strategic Framework for Action on Palliative and End of Life Care*** (2015) - <http://www.gov.scot/Topics/Health/Quality-Improvement-Performance/peolc/SFA>

### OVERALL PROGRESS IN HOSPICE AND PALLIATIVE CARE

The Evidence Summary of the *Strategic Framework for Action* makes the following points:

Scotland has benefited from the action plan known as *Living and Dying Well*, published in 2008. In 2012 a review of *Living and Dying Well* was positive about the progress that had been made, referring to ‘compelling evidence of a high level of energy and commitment on the part of individuals and organisations’. Scotland has a wide array of specialist palliative care services, across community and hospital settings. In November 2014 a full set of *Palliative Care Guidelines* was issued for Scotland. In December 2014 the Scottish Government published guidance on *Caring for People in the last Days and Hours of Life*.



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Scotland has a rich ‘community of practice’ around palliative care. NHS, social services and care home workers deliver care to people with advanced illness and to their families, using well developed palliative care approaches. Important work is undertaken by the Scottish Partnership for Palliative Care and its public engagement arm Good Life, Good Death, Good Grief. Independent hospices make major contributions to their local communities. National charities provide services, leadership and support for innovation. Academic palliative care expertise exists in Universities and Colleges and there are established training and accreditation programmes. But we know there are gaps in our knowledge and inadequacies in coverage. The Strategic Framework points the way to addressing these by promoting local implementation plans against a broad national vision.

**2008** Audit Scotland Report - ***Review of Palliative Care Services in Scotland*** - [http://www.audit-scotland.gov.uk/docs/health/2008/nr\\_o8o821\\_palliative\\_care.pdf](http://www.audit-scotland.gov.uk/docs/health/2008/nr_o8o821_palliative_care.pdf)

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**2010** ***Living and Dying Well: building on progress*** - <http://www.gov.scot/Resource/Doc/340076/0112559.pdf>

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**2011** ***Shaping bereavement care - A Framework for Action on Bereavement Care in NHS Scotland*** - [http://www.sehd.scot.nhs.uk/mels/cel2011\\_09.pdf](http://www.sehd.scot.nhs.uk/mels/cel2011_09.pdf)



- 
- 2011** *Palliative Care (Scotland) Bill* introduced into Parliament and then withdrawn in December 2010 - <http://www.audit-scotland.gov.uk/report/a-review-of-palliative-care-services-in-scotland>.
- 
- 2011** Scottish Partnership for Palliative Care begins the **Good Life, Good Death, Good Grief** initiative - <http://www.goodlifedeathgrief.org.uk/>
- 
- 2012** *Living and Dying Well: Reflecting on Progress* - <http://www.gov.scot/Topics/Health/Quality-Improvement-Performance/peolc/ProgressReport>
- 
- 2013** *Palliative Care Guidelines for Scotland* are published - <http://www.palliativecareguidelines.scot.nhs.uk/>
- 
- 2015** *Scottish Parliament Report – We Need to Talk about Palliative Care* - <http://www.scottish.parliament.uk/parliamentarybusiness/CurrentCommittees/94230.aspx>
- 
- 2015** *Children in Scotland requiring Palliative Care: identifying numbers and needs (The ChiSP Study)* - <http://www.york.ac.uk/inst/spru/research/pdf/chisp.pdf>
- 
- 2015** *“No place for fatalism” Third sector contributions to improving older people’s experiences of declining health, bereavement and death”* - <http://www.jitscotland.org.uk/wp-content/uploads/2015/04/SiT-EvRev-No-Place-for-Fatalism.pdf>
- 
- 2015** *Grasping the Nettle: What action can we take to improve palliative and end of life care in Scotland?* Scottish Partnership for Palliative Care. <http://www.palliativecarescotland.org.uk/news/news/grasping-the-nettle/>
- 
- 2016** *Palliative and end of life care in Scotland: The rationale for a public health approach* - <http://www.scotphn.net/projects/palliative-and-end-of-life-care-pelc/palliative-and-end-of-life-care-pelc/>



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### DEVELOPMENT OF HOSPICE AND PALLIATIVE CARE IN DIFFERENT HEALTH AND SOCIAL CARE SETTINGS

This is a strong theme in several recent documents: The 2015 - Scottish Parliament Report – *We Need to Talk about Palliative Care* and also *Scottish Government’s 2015 Strategic Framework for Action on Palliative and End of Life Care*. It will be influenced in particular by the creation of the Integrated Boards for Health and Social Care from April 2016, which will be responsible for the commissioning of palliative care in Scotland. See: <http://www.gov.scot/Topics/Health/Policy/Adult-Health-SocialCare-Integration>

### EXPANSION FROM A FOCUS ON CANCER PATIENTS TO ADDRESS THE NEEDS OF ‘NON-CANCER’ PATIENTS

This is widely accepted as a policy principle, it is acknowledged in the **Strategic Framework for Action** and is a particular focus of the work of Marie Curie Scotland in the period, for example, the report **Triggers of Palliative Care** - <https://www.mariecurie.org.uk/globalassets/media/documents/policy/policy-publications/june-2015/triggers-for-palliative-care-full-report.pdf>

**2008 *Living and Dying Well with Advanced Heart Failure*** - <http://www.palliativecarescotland.org.uk/content/publications/LivingAndDying.pdf>

---

**2014 *Optimising Older People’s Quality of Life: an Outcomes Framework*** - one of four outcomes is optimising quality of end of life, and there is an associated logic model - <http://www.healthscotland.com/documents/23946.aspx>

---

**2014 *‘Somewhere to Go and Something to Do’. Active and Healthy Ageing – An Action Plan for Scotland 2014 – 2016*** - incorporates elements of health promoting palliative care alongside active aging narrative - <http://www.jitscotland.org.uk/resource/active-healthy-ageing/>



# Policy









## 08. Development of palliative care policy since 2006

### MOST IMPORTANT LEGAL OR POLICY CHANGES AFFECTING THE DEVELOPMENT OF HOSPICE AND PALLIATIVE CARE

**Living and Dying Well** (2008) - <http://www.gov.scot/Publications/2008/10/01091608/0>

**Strategic Framework for Action on Palliative and End of Life Care** (2015) - <http://www.gov.scot/Topics/Health/Quality-Improvement-Performance/peolc/SFA>

Key policy and legal changes to palliative care in Scotland in the period 2006-15 include:

- The development of the Electronic Palliative Care Summary (ePCS) to support the sharing of vital clinical information across care settings. This electronic anticipatory care plan has been further developed and widened to include all patients with long term conditions - the Key Information Summary (KIS)
- The development and roll out of a national integrated Do Not Attempt Cardio Pulmonary Resuscitation (DNACPR) policy across all care settings and a similar (though broader) process exists for children (Children and Young Peoples Acute Deterioration Management Plan [CYPADM])
- The implementation of a national incentive system to encourage the identification of people with palliative care needs in primary care and planning to meet those needs.
- Improvements in palliative care in care homes through educational support from hospices and NHS Boards.
- Agreement of national referral criteria for specialist palliative care.
- The development of national clinical guidelines to support the practice of generalists.
- The development of rapid discharge services.
- The development and piloting of a “Structured Scottish Response” (SSR) to the care of patients in hospital whose condition is deteriorating and whose recovery is uncertain, which prompts appropriate communication and planning with patient and family.
- Improvements in professional knowledge and awareness of care in the last days and hours, through educational activities associated with the Liverpool Care Pathway.
- The establishment of an alliance to promote more openness in Scottish society about death, dying and bereavement <https://www.goodlifedeathgrief.org.uk>.
- The development of local services directories and the creation of the national Palliative Care zone for patients and families on the NHS Inform portal. See - <http://www.palliativecarescotland.org.uk/content/about/>
- New arrangements on the registration and certification of deaths in Scotland were introduced on 13 May 2015. These include the establishment of an independent review service run by Healthcare Improvement Scotland.



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### **DEVELOPMENT OF A NATIONAL PALLIATIVE CARE CONSENSUS**

Significant meetings with stakeholders and policy makers have taken place to develop palliative care strategies: A National Advisory Group for palliative care was established in 2014 to advise the Cabinet Secretary for Health and Sport on the development of a new Strategic Framework for Action on Palliative and End of Life Care. In addition, a Stakeholder Group was formed to gather ideas from a wider constituency.

### **DEVELOPMENT OF AN ADVOCACY FRAMEWORK FOR INTEGRATING PALLIATIVE CARE INTO THE HEALTH CARE SYSTEM**

Through the Strategic Framework for Action, 2016-21 and in the efforts of various third sector and professional organisations.

### **STRATEGIES TO IMPROVE POLITICAL AWARENESS AND GOVERNMENT RECOGNITION OF PALLIATIVE CARE**

A Cross Party Group on Palliative Care meets four times per year at the Scottish Parliament and considers a wide range of business. Minutes of past meetings (since 2007) can be found at [http://www.palliativecarescotland.org.uk/content/cross\\_party\\_previous\\_meetings/](http://www.palliativecarescotland.org.uk/content/cross_party_previous_meetings/)

The Scottish Partnership for Palliative Care, Marie Curie Scotland, Macmillan and a range of other third sector organisations engage in advocacy for palliative and end of life care.



## 9. Perceived barriers to the development of hospice and palliative care

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These are listed in a section of *Grasping the Nettle* (pp14-15) and include: the complexity of need, the range of organisations' involved in a person's care, the varied trajectories of illness and dying, variations in need relating to stage of life, the problems faced by informal carers, workforce limitations, negative media coverage and poor public understanding, cultural attitudes to death and constraints affecting nursing homes.



## 10. Perceived opportunities for the development of hospice and palliative care

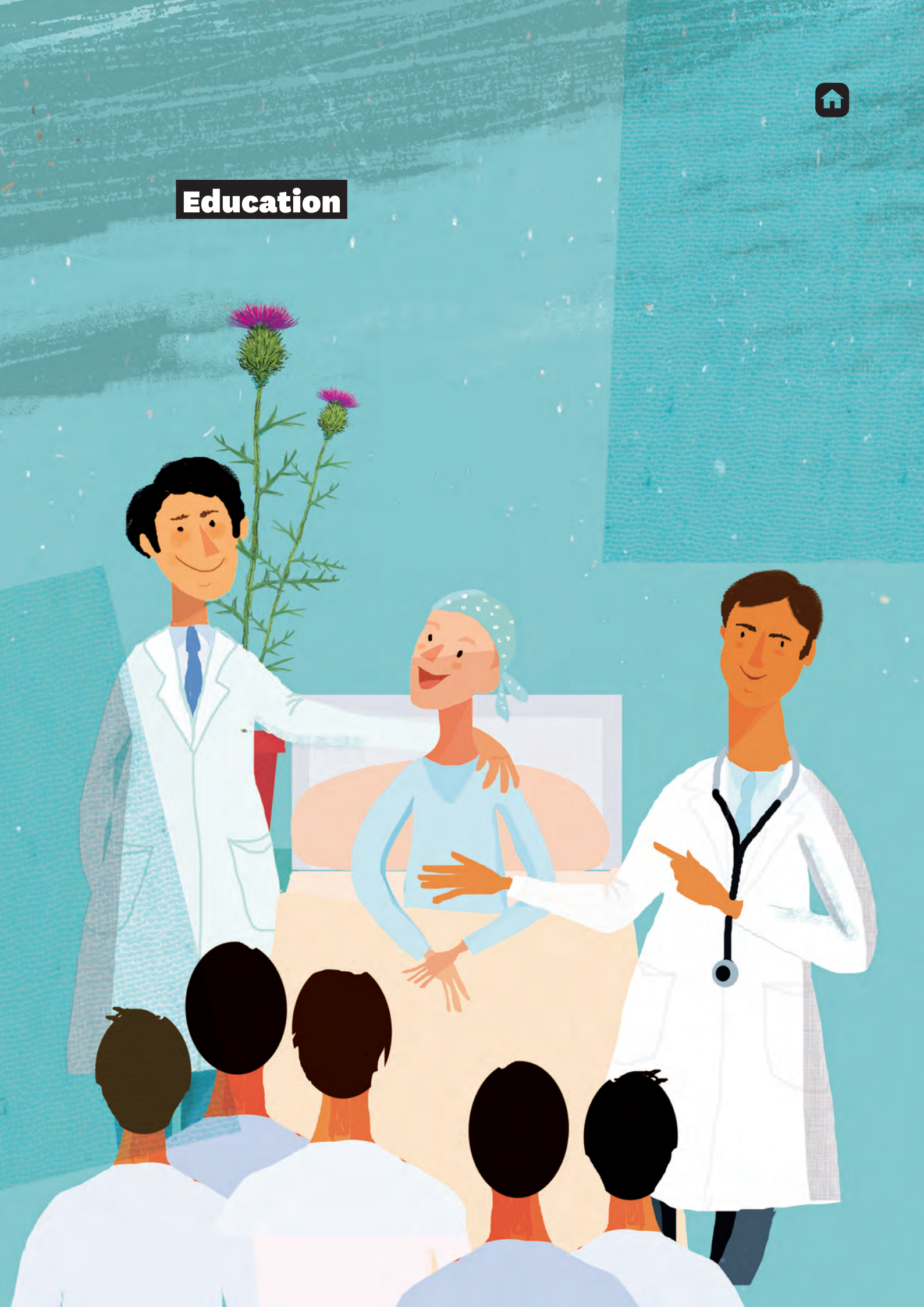
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These can be summarised in the 10 Commitments contained in the *Strategic Framework for Action* and which cover the period 2016 – 21:

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.



# Education







## 11. Developments in palliative care education and training since 2006

### GENERAL DEVELOPMENTS IN PALLIATIVE CARE EDUCATION AND TRAINING INITIATIVES

The *Strategic Framework for Action* contains a specific commitment (number 3) on education, which states: ‘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’.

The group received strong support from the Scottish University Teaching Deans who are now committed to integrating end-of-life care teaching in the teaching of various specialties in Scottish Medical Schools

### SPECIFIC DEVELOPMENTS IN UNDER-GRADUATE PALLIATIVE CARE EDUCATION INITIATIVES

Academic leaders from the five Scottish Universities with medical schools met together to improve palliative medicine teaching. From the General Medical Council’s document *Tomorrow’s Doctors* they identified a number of key learning outcomes, which had a clear relevance to palliative care and which were practical for medical students and also foundation doctors to achieve. The group received strong support from the Scottish University Teaching Deans who are now committed to integrating end of life care teaching in the teaching of various specialties in Scottish Medical Schools.

A number of teaching resources are now held at the website of the Primary Palliative Care Research Group in Edinburgh, and assessment questions have also been developed. See:

Linklater GT, Bowden J, Pope L, McFatter F, Hutchison SMW, Carragher PJ, Walley J, Fallon M & Murray SA. Developing learning outcomes for medical students and foundation doctors in palliative care: A national consensus-seeking initiative in Scotland. *Medical Teacher*, 2014, 1-6.

This has resulted in better integration of palliative care training in the general medical school curricula.



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### **SPECIFIC DEVELOPMENTS IN POST-GRADUATE PALLIATIVE CARE EDUCATION INITIATIVES**

The following publications were produced in Scotland and written for postgraduate education in generalist palliative care:

Clark, D Graham, F Centeno, C (2015) Changes in the world of palliative care. *Medicine* 43(12): 696-98.

Bowden J, Dempsey K, Boyd K, Fallon M & Murray SA. Are newly qualified doctors prepared to provide supportive and end of life care? A survey of Foundation Year 1 doctors and consultants. *Journal of the Royal College of Physicians* 2013; 43: 24-8.

Mead GE, Cowey E & Murray SA. Life after stroke – is palliative care relevant? A better understanding of illness trajectories after stroke may help clinicians identify patients for a palliative approach to care. *International Journal of Stroke*, 2013; 8: 447-448.

Murray SA & Boyd K. Using the ‘surprise question’ can identify people with advanced heart failure and COPD who would benefit from a palliative care approach. *Palliative Medicine* 2011; 25: 382.

Boyd K & Murray SA. Recognising and managing key transitions in end of life care. *British Medical Journal* 2010; 341:c4863.

### **TRANSLATION OF PALLIATIVE CARE DOCUMENTS OR OTHER MATERIALS**

The Supportive and Palliative Care Indicators Tool (SPICT) has been in development since 2010 as a collaborative project between NHS Lothian and The University of Edinburgh Primary Palliative Care Research Group. Now widely known, with international collaborators in Australia, North and South America and Europe, it is a guide to identifying people with one or more advanced conditions, who have deteriorating health and a risk of dying – and who might benefit from the palliative care approach. The SPICT has been translated into several languages.

### **INITIATIVES TO DEVELOP HEALTHCARE PROFESSIONAL LEADERSHIP IN PALLIATIVE CARE**

There is ongoing support from Macmillan Cancer Relief and Marie Curie for GP facilitators in some regions.

### **OFFICIALLY RECOGNIZED MEDICAL CERTIFICATION**

Palliative Medicine gained specialty recognition in 1987.





## 12. Opioids

<p>Is there a standard process for the prescription and acquisition of opioids in Scotland? Please describe.</p>	<p>Yes</p>
<p>Describe the standard process</p>	<p>Access to opioids is dependant initially on the drug, strength and formulation of the preparation. For instance, co-codamol i.e. paracetamol and codeine 500mg/8mg is available without prescription from a pharmacy only. Higher-strength opioids are available on prescription by an approved clinician, including allied health professionals.</p>
<p>What are the restrictions on opioid prescriptions in Scotland?</p>	<p>The prescriber must be suitably authorised to prescribe said products. There are a number of national and local guidelines on the appropriate opioids to prescribe and associated issues such as recommended maximum duration of prescriptions but these are not mandatory.</p>
<p>What specialties can prescribe opioids in your country?</p>	<p>All appropriately authorised prescribers may prescribe opioids. All medical practitioners and suitably qualified non-medical prescribers.</p>



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Is codeine available in a variety of strengths, formulations and as an ingredient in multi-ingredient preparation(s)?	Yes
Is Hydrocodone available?	Yes
Is Morphine available?	Yes
Is Hydromorphone available?	Yes
Is Oxycodone?	Yes
Is Meperidine available? Known as pethidine in UK	Yes
Is Fentanyl available?	Yes
Is Sufentanil available?	No
Is Methadone available?	Yes
Is Levorphanol available?	No
Is Oxymorphone available?	No
Is Transdermal Fentanyl available?	Yes
Is Diamorphine available?	Yes



## 13. Published national documents relating to palliative care standards and norms

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- 2002** *Clinical Standards for Specialist Palliative Care* - <http://www.palliativecarescotland.org.uk/content/publications/ClinicalStandardforSPC.pdf>
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- 2005** *National Care Standards for Hospice Care* - <http://www.palliativecarescotland.org.uk/content/publications/2005-09-National-care-standards-for-hospice-care.pdf>
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- 2009** *HIS National Standards for Neurological Services* - includes a standard about access to palliative care - [http://www.scottishneurological.org.uk/content/res/final\\_QIS\\_standards.pdf](http://www.scottishneurological.org.uk/content/res/final_QIS_standards.pdf)
- 
- 2010** *HIS Clinical Standards for Heart Disease* - [http://www.healthcareimprovementscotland.org/our\\_work/cardiovascular\\_disease/heart\\_disease\\_services/heart\\_disease\\_standards.aspx](http://www.healthcareimprovementscotland.org/our_work/cardiovascular_disease/heart_disease_services/heart_disease_standards.aspx)
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- 2013** *Palliative Care Guidelines for Scotland* - <http://www.palliativecareguidelines.scot.nhs.uk/>
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- 2015** *Strategic Framework for Action on Palliative and End of Life Care* - <http://www.gov.scot/Topics/Health/Quality-Improvement-Performance/peolc/SFA>
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- 2015** *HIS Standards of Care for Older People in Hospital* - includes a lot of references to palliative care - [http://www.healthcareimprovementscotland.org/our\\_work/person-centred\\_care/resources/opah\\_standards.aspx](http://www.healthcareimprovementscotland.org/our_work/person-centred_care/resources/opah_standards.aspx)
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- 2016** *National Cancer Control Strategy: Beating Cancer: ambition and action* - <http://www.gov.scot/Publications/2016/03/9784>
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### NATIONAL HIV/AIDS STRATEGY

An **HIV Action Plan in Scotland** from Scottish Government covers the period December 2009 – March 2014. It makes no mention of palliative care.

### NATIONAL PRIMARY HEALTH CARE STRATEGY

The Scottish Government issued guidance for a new **Palliative Care Directed Enhanced Service** in Scotland which came into effect from 1 April 2012 - [www.sehd.scot.nhs.uk/pca/PCA2012\(M\)06.pdf](http://www.sehd.scot.nhs.uk/pca/PCA2012(M)06.pdf). The DES Directions setting out the legal obligation on Health Boards were issued under cover of circular PCA2012(M) 04 and came into force on 1 April 2012. The goal of the initiative is to promote earlier identification and intervention for those who might benefit from palliative care. This required participating practices to:

1. Ensure that they include patients identified with palliative and end of life care needs, irrespective of diagnosis, on their Quality Outcome Framework (QOF) palliative care register.
2. Ensure that patients on the QOF palliative care register have been assessed and that an initial care plan has been compiled and an electronic palliative care summary completed using the standardised Electronic Palliative Care Summary (ePCS) or equivalent where practices are not yet enabled to use ePCS. The ePCS or equivalent should be completed and made available to professionals involved in the patient's care in the out of hours period within 4 weeks of inclusion on the register.
3. Engage in a programme of reflective practice involving the wider multidisciplinary team.



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A **National Clinical Strategy for Scotland** was published by the Scottish Government in 2016, it makes two references to palliative care - <http://www.gov.scot/Publications/2016/02/8699>

A **National Review of Primary Care Out of Hours Services** was published by the Scottish Government in 2015 - <http://www.gov.scot/Publications/2015/11/9014>

It contains a four-point recommendation on palliative care

1. People at the end of life and their carers should be able to directly access care and assistance, by contacting a local helpline on a 24/7 basis, without recourse to national NHS 24 triage - in order to secure swift, effective and compassionate care.

2. Palliative care patients and their carers should have extended access to responsive and timely community nursing support, including Macmillan and Marie Curie nurse practitioners, alongside allied health professionals (AHPs), as required.

3. Local care pathways for palliative care should be developed systematically, be clearly understood by service users and providers, implemented effectively, and quality assured. There should be an emphasis on home, and hospice care at home support, wherever possible.

4. All of the former recommendations to be underpinned by safe and secure shared electronic records and comprehensive anticipatory care plans.



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### **SYSTEMS OF AUDITING, EVALUATION OR QUALITY ASSURANCE THAT MONITOR THE STANDARD OF PALLIATIVE CARE**

Health Improvement Scotland engages in programmes to support quality improvement and quality assurance - [http://www.healthcareimprovementscotland.org/our\\_work/person-centred\\_care/palliative\\_care.aspx](http://www.healthcareimprovementscotland.org/our_work/person-centred_care/palliative_care.aspx). HIS has produced a set of palliative care indicators that focus on identification; assessment and care planning; accessing patient information, and place of death - [http://www.healthcareimprovementscotland.org/our\\_work/person-centred\\_care/palliative\\_care/palliative\\_care\\_indicators.aspx](http://www.healthcareimprovementscotland.org/our_work/person-centred_care/palliative_care/palliative_care_indicators.aspx). HIS has also published a set of Palliative Care Guidelines that provide practical, evidence based or best practice advice on the management of pain, symptom control, palliative emergencies and end of life care in a readily usable format. The guidelines assist both generalist and specialist providers of care in the management of patients at the end of their lives and provide the evidence base for improvements in palliative care services across all health and care settings.

The Care Inspectorate regulates and inspects care services in Scotland including care homes for adults and care at home services - <http://www.careinspectorate.com/>

### **OPIOID LEGISLATION / PAIN GUIDELINES**

The Scottish Intercollegiate Guidelines Network - <http://www.sign.ac.uk/> has produced guidelines on the control of pain in adults with cancer (2008) and the management of chronic pain (2013).

### **FUNDING OF PALLIATIVE CARE SERVICES**

£3.5m has been allocated for the implementation of the Strategic Framework for Action on Palliative and End of Life Care

The Scottish Parliament Health and Sport Committee inquiry into palliative care (2015) required all Boards to say something about their expenditure on palliative and end of life care but found the response and quality of information received was mixed. A number of Boards could not separate out general palliative care expenditure from other areas of spending - <http://www.scottish.parliament.uk/parliamentarybusiness/CurrentCommittees/94230.aspx>

A funding call of £1.4m for palliative care research, issued in 2015 by Marie Curie, the Chief Scientist's Office and the Motor Neurone Disease Association ring-fenced a minimum of £450,000 for work led by Principal Investigators in Scotland - <https://www.mariecurie.org.uk/research/funding-research/marie-curie-research-grants-scheme/2016-call-for-applications>



# Socio-cultural









## 14. Changes in socio-cultural, ethical, moral attitudes since 2006

### CHANGE IN PUBLIC AWARENESS OR PERCEPTION OF HOSPICE AND PALLIATIVE CARE

*Good Life, Good Death, Good Grief* (GLGDGG) was established in January 2011 when the Scottish Partnership for Palliative Care (SPPC) invited interested individuals to join a small stakeholder group. This stakeholder group worked with SPPC staff to establish and build up an identity for *Good Life, Good Death, Good Grief*. SPPC staff undertook initial work relating to establishing terms of reference, work plan and communications strategy for the alliance (GLGDGG), inviting members and publicising the alliance. The first members of the alliance joined in November 2011 (from - <http://www.goodlifedeathgrief.org.uk/content/history/>).

Just over 60% of members are from the health and social care sectors, with just under 40% of members coming from a range of other backgrounds

GLGDGG is an alliance of individuals and organisations working towards the common aim of raising public awareness of ways of dealing with death, dying and bereavement, and promoting community involvement in death, dying and bereavement. GLGDGG has 947 members (661 individuals and 286 organisations). Organisational members include all NHS Boards, all independent Scottish Hospices, and many high profile national charities such as Parkinson's UK, Age Scotland and Marie Curie. Just over 60% of members are from the health and social care sectors, with just under 40% of members coming from a range of other backgrounds including academia, education, faith based organisations, the arts and law. GLGDGG strives to evaluate its work by: gathering activity data, collecting data relating to a range of relevant proxy indicators, systematically reviewing activity and identifying learning, and undertaking formal evaluation when feasible within the limits of available resources - [http://www.scotphn.net/wp-content/uploads/2016/03/2016\\_02\\_26-Briefing-Paper-5-SPPC-GLGDGG.pdf](http://www.scotphn.net/wp-content/uploads/2016/03/2016_02_26-Briefing-Paper-5-SPPC-GLGDGG.pdf)



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