Scottish Partnership for Palliative Care



Annual Review 2013-2014





Kenny Steele, Chairman of the Scottish Partnership for Palliative Care

Chairman's Report

The Scottish Partnership for Palliative Care continues to be a key player in improving the quality of palliative care in Scotland. How we care for those who are dying is a fundamental measure for the quality of our health and social care system. How we help to support those who have been bereaved is of equal importance.

The Partnership is leading the way, together with the support of our members, to improve the

quality of palliative care we and our families can expect. The *Good Life, Good Death, Good Grief* initiative is helping to break down some of the social and cultural barriers that can prevent all of us (including health and care professionals) from being open and honest about dying.

100% of us will die. We all therefore should have an interest in supporting the Partnership deliver its mission.

For a very small organisation I continue to be hugely impressed by the results that the Partnership achieves. That is largely down to the dedicated staff team and their ability to harness and co-ordinate the energies of the members and my thanks to them for another excellent year. Thanks also to our funders for continuing to support our work and recognising the important leadership role that the Partnership performs.

Finally, thanks to my fellow Council members for their help in steering the Partnership through 2013-14.

Future plans:

During 2013-14 the Partnership reviewed and updated its strategy identifying the following strategic objectives which will guide its work over the next 3 – 5 years. The Partnership will:

- 1. Provide strategic leadership in improving the experience of death, dying and bereavement in Scotland. By this we mean; maintaining a whole system perspective and associated intelligence; advocating the importance and value of palliative and end of life care; contributing to the development of strategic thinking and national policy and brokering strategic collaboration.
- 2. Identify, and support the spread of, good practice and innovation.
- 3. Promote public and professional awareness, understanding and knowledge of ways to improve death, dying and bereavement and promote public dialogue around these issues.
- 4. Encourage effective planning for better death, dying and bereavement by the public, and by professionals together with patients and families, at all stages of life.
- 5. Work to ensure that the experiences of the public, patients and families inform the development and implementation of policy and practice.

Chief Executive's Report

Around 54,000 people died in Scotland during 2013-14. Of these around 70% had palliative care needs. Many more thousands of people were affected by the death of a friend, colleague or family member.

Palliative care is an approach that improves the quality of life of patients and their families facing the problems associated with life-threatening illness, through the prevention and relief of



Mark Hazelwood, Chief Executive of the Scottish Partnership for Palliative Care

suffering by means of early identification and impeccable assessment and treatment of pain and other problems, physical, psychosocial and spiritual, including coping with bereavement.

The Scottish Partnership for Palliative Care provides a national forum for the development and implementation of palliative care strategy and good practice, a comprehensive communication network, and a source of expert advice and guidance for practitioners, service managers, planners and policy makers. It works with its member organisations, with the Scottish Government and with local, regional and national bodies to influence policy and to encourage the equitable and accessible provision of palliative care to patients and families.

Key Achievements During 2013-14

The Partnership continued to manage and support a collaboration between Scotland's health boards to review and develop palliative care clinical guidelines. The guidelines are a very practical tool for non-specialist health care workers and will be widely used to support the quality of palliative care in different settings. The collaboration avoids local duplication of work.

The Partnership continued to work with NHS inform to provide the Palliative Care Zone. This web-resource provides quality information on palliative care to the Scottish public.

Around a third of people in Scotland's acute hospitals are in their last year of life. During the year the Partnership completed work with NHS Boards and the Scottish Patient Safety Programme to develop an approach to improving the care of patients in hospital whose condition is deteriorating and whose recovery is uncertain. As well as rapidly identifying reversible causes of deterioration the approach also promotes early and sensitive communication with patients and families about their preferences for care in the event of further deterioration.

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The Partnership continued to provide advice and information to the *Reshaping Care for Older People* improvement network, producing a themed newsletter on palliative care. The Partnership worked to ensure that optimising the quality of end of life was included as an outcome for this programme of work. The Partnership also provided input to the drafting of the second national dementia strategy and a taskforce examining the future of residential care in Scotland.

Good Life, Good Death, Good Grief, an initiative of the Partnership, is a broadbased alliance promoting more openness about death, dying and bereavement. Over time this alliance will make it easier for people in Scotland to think and plan ahead towards death and dying. As a result fewer people will die without having made a will, more people will have discussed their preferences for care with their doctors and will have spoken to friends and family about their wishes for funerals and how they would wish to be remembered. People will be better equipped to support friends, family and colleagues who are bereaved. By the end of March 2014 Good Life, Good Death, Good Grief had over 830 members, of which nearly 239 (up 27% during the year) were organisations and the remainder interested individuals (up 29% over the year). An event for stakeholders was run in November. 20 small grants were made to support activity in the national awareness week which was run in May. Over 50 events took place during the awareness week and media coverage was generated and social media activity spiked. More details about Good Life, Good Death, Good Grief are at www.goodlifedeathgrief.org.uk

The Partnership continued to identify and promote good practice in palliative care. The Partnership continued to publish *UPDATE*, a monthly e-bulletin which equips practitioners with the latest palliative care news and best practice. This generated over 33,000 views. The Partnership also ran a busy calendar of constituency group meetings which promoted the sharing of good practice and problem solving. In October the Partnership ran a successful annual conference attended by over 230 people.

At the request of the Scottish Government the Partnership continued to provide a secretariat/ project management function for the National Advisory Group for *Living and Dying Well*. The Partnership ran a subgroup to review the Neuberger Report *More Care Less* Pathway and to produce interim guidance on care in the last days and hours of life for NHS Boards and other providers.

In February the Partnership, together with Marie Curie Cancer Care, ran a 'question time' style event with MSP party health spokespeople and palliative care experts which reviewed progress on improving palliative care over the past 5 years and also sought to identify future challenges and solutions.

Core income and expenditure account for the year ended 31 March 2014







6 Scottish Partnership for Palliative Care

Office Bearers at 31 March 2014

Honorary President Dr Derek Doyle OBE MB ChB FRCS FRCP FRCGP **Honorary Vice President** Professor Sir Kenneth Calman KCB MD FRCS FRSE

Chairman

Kenny Steele Chief Executive, Highland Hospice

Deputy Chairman

Helen Simpson Chief Executive, ACCORD Hospice

Honorary Treasurer Jacquie Lindsay

Hospice Lecturer, St Margaret of Scotland Hospice

Council Members

Rebecca Patterson

Dr Gordon Canning	Consultant in Palliative Medicine St Andrew's Hospice
Dr Libby Ferguson	Consultant in Palliative Care Marie Curie Hospice, Glasgow
Shirley Fife	Nurse Consultant Cancer & Palliative Care NHS Lothian
Linda Kerr	Nurse Specialist in Palliative Care NHS Ayrshire and Arran
Dr Peter Kiehlmann	General Practitioner NHS Grampian
Maria McGill	Chief Executive Children's Hospice Association Scotland
Dr Gordon McLaren	Consultant in Public Health Medicine NHS Fife
Tanith Muller	Parliamentary & Campaigns Officer Scotland Parkinson's UK
Dr Euan Paterson	General Practitioner NHS Greater Glasgow and Clyde
Helen Simpson	Chief Executive ACCORD Hospice
Elaine Stevens	Lecturer in Cancer and Palliative Care Independent Assoc. of Nurses in Palliative Care
Nichola Summers	Divisional General Manager for Scotland Marie Curie Cancer Care
Observers	
Claire Henry	National Council for Palliative Care
Sinéad Power	Scottish Government Health Directorates
Craig White	Scottish Government Health Directorates
Staff	
Derek Blues	Project Manager
Pauline Britton	Publications and Group Liaison Officer
Susan Diotaiuti	Executive Assistant/PA to Chief Executive
Claire Femister	Finance and Administration Manager
Mark Hazelwood	Chief Executive

Policy and Communications Manager



Scottish Parliament building

Cross Party Group in the Scottish Parliament on **Palliative Care**

The Scottish Partnership for Palliative Care provides the secretariat for the Cross Party Group in the Scottish Parliament on Palliative Care.

The Cross Party Group provides an opportunity for MSPs from all parties, members of the public, and representatives from various organisations to meet and discuss a shared interest in palliative care. All are welcome to join or attend meetings of the Cross Party Group.

Topics presented upon during 2013-2014 included: Palliative care for people living with nonmalignant illness; Palliative and end of life care in hospitals - a structured response to deteriorating patients; The relevance of 'assets based' approaches to palliative and end of life care in Scotland; Caring for people who are dying: reflections on the Liverpool Care Pathwav.

Convener: Michael McMahon MSP

Vice-conveners: Jamie McGrigor MSP and Dennis Robertson MSP

Secretary/ Treasurer: Mark Hazelwood, Scottish Partnership for Palliative Care

If you would like to attend a future meeting please contact Pauline Britton

pauline@palliativecarescotland.org.uk

Good Life, Good Death, Good Grief

Good Life, Good Death, Good Grief is the SPPC-led alliance working to make Scotland a place where people can be open about death, dying and bereavement. The alliance now has over 800 members and a strong social media following. Key activities that took place in 2013-2014 included:



- Running a small grants programme in March to support members to undertake activities, events or projects aimed at helping Scotland to become a place where people are more open about death, dying and bereavement. Twenty grants were made.
- Attracting our first volunteer, Joan Adam, who worked as a Macmillan Nurse Specialist and then a lecturer in palliative care for 20 years. She has a particular interest in using her skills and expertise to run workshops relating to death, dying and bereavement for volunteers.
- Developing the website to include an interactive virtual *Before I Die* wall and some intriguing new content to draw people to the factual areas of the website.
- · Producing a 'death trivia' factsheet resource for members to use.
- Initiating the first ever death awareness week in Scotland in May. 20 events were held to mark Awareness Week and 33 Before I Die walls were created across the country.
- Working with *Just Festival* to hold two *Dining with Death* events during the Edinburgh Festival Fringe in August. Just Festival went on to run a continuing series of monthly death cafes in Edinburgh.
- Scottish Parliament recognition of *GLGDGG* work when seven MSPs voiced their support for more openness during a debate on the 18 September.
- Working with the *100% Project* to bring Before I Die walls to the Scottish Government to mark Hospice Care Week 2013 in October.
- Conceptualising and developing *To Absent Friends*, a people's festival of storytelling and remembrance, including creating *To Absent Friends: an exhibition in words and pictures*.
 Creating the *To Absent Friends* wall an opportunity for people to publicly memorialise dead loved ones within a participatory public art experience.
- Organising a members networking event attended by over 100 people from a variety of organisations.



A Before I Die wall outside the Scottish Parliament HQ



Part of the To Absent Friends exhibition



To Absent Friends wall

Scottish

Partnership

for Palliative Care

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