

Scottish Partnership for Palliative Care



Annual Review 2011-2012



Kate Lennon, Chairman of the Scottish Partnership for Palliative Care

Future plans:

During 2012-13 the Partnership's work will include:

- continuing to support the NHS Board collaboration to review and develop palliative care clinical guidelines
- provision of information for the public about palliative care, in collaboration with NHS inform
- production of a resource to support improvement of palliative care in care homes
- continuing to provide palliative and end of life care input to Scottish Government workstreams on dementia and older people
- continuing to develop *Good Life, Good Death, Good Grief* the broad-based alliance to promote public openness around dying, death and loss.

Chairman's Report

Although I have been involved with the Partnership since 2006, this is my first opportunity and privilege to be reporting as Chairman of the Partnership to the members and other stakeholders. In all those years of involvement, I have been hugely impressed by the commitment of everyone involved with this organisation to the idea of palliative care, to widening access and to improving the standard for all who need that care now and for the growing number of Scottish people who are likely to need it in the future.

That commitment to, and enthusiasm for success in our key achievements is unquestioned. However at times the process of reaching our achievements can be fraught with problems, dragged down by funding difficulties, over burdened by bureaucracy and slowed down so that there is a danger of stagnation.

As Chairman of the Partnership, with fellow Council members, staff and member organisations, we are committed to ensuring that all the hopes and future plans which we talk about for palliative care translate into concrete improvements in service to the people of Scotland.

In the year ahead one of the most exciting strands of work for us is continuing to develop and promote public openness around dying, death and loss. The aims of the alliance, *Good Life, Good Death, Good Grief*, is to encourage and help us all to prepare for what lies ahead, by putting simple measures in place such as making a will, writing down our wishes and being more willing to offer company to those facing bereavement and terminal illness. Quite simply, to be more comfortable with this experience that we are all going to share.

Finally I offer my congratulations and sincere thanks to the hard working small and perfect together staff team of the Partnership and to my Council colleagues for their ongoing commitment to the vision of palliative care for all.

Director's Report

About Palliative and End of Life Care

Around 54,000 people died in Scotland during 2011-12. Of these around 38,000 had palliative care needs. Many more thousands of people were affected by the death of a friend, colleague or family member. At any one time around a third of people in Scottish hospitals are in their last year of life. 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 suffering by means of early identification and impeccable assessment and treatment of pain and other problems, physical, psychosocial and spiritual, including coping with bereavement.

Palliative care is not just about people with cancer – it is about care for all people with life-threatening illness. Specialist palliative care focuses on people with complex palliative care needs (eg complex pain management or psychological support) and is provided by a team of professionals who specialise in palliative care (eg consultants in palliative medicine and clinical nurse specialists in palliative care). Hospices are an example of a specialist palliative care service. General palliative care forms part of the routine care of patients and support for carers. It may be part of the work of a range of health and social care practitioners including GPs, district nurses, care assistants and hospital staff and takes place in a range of settings.

About the Scottish Partnership for Palliative Care

Through its activities 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 appropriate local, regional and national bodies to influence policy and to encourage the equitable and accessible

(Continued overleaf)



Mark Hazelwood, Director of the Scottish Partnership for Palliative Care

Future plans:

The Partnership has agreed five strategic objectives for the next three years:

- support the ongoing implementation of *Living and Dying Well* and other relevant national initiatives
- inform and influence national policy relevant to palliative care
- identify, promote and share good practice in the planning and provision of palliative care
- promote public and professional understanding of palliative and end of life care, and more open discussion in society of dying, death and bereavement
- maintain and develop the Partnership in order to be able to deliver the other four strategic objectives.

provision of palliative care services to patients and families in Scotland on the basis of need not diagnosis. The developments of the year under review and those immediately preceding provide evidence of the Partnership's continuing influence and success.

Key Achievements during 2011-12

During 2011-12 the Partnership carried out a range of activities which both directly and indirectly promoted improved palliative care and supported implementation of the Scottish Government's action plan on palliative and end of life care, *Living and Dying Well*.

The Partnership initiated and supported a multi-Board collaboration 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 worked with NHS inform to launch the Palliative Care Zone. This web-resource provides quality information on palliative care to the Scottish public.

The Partnership provided advice and information to the *Reshaping Care for Older People* improvement network. This network (consisting of local partnerships between NHS Boards, local authorities and voluntary organisations) is working to transform services for older people, with an emphasis on enabling them to live independently in the community for longer.

In November 2011 the Partnership launched *Good Life, Good Death, Good Grief*, a broad-based 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. More details are available at www.goodlifedeathgrief.org.uk

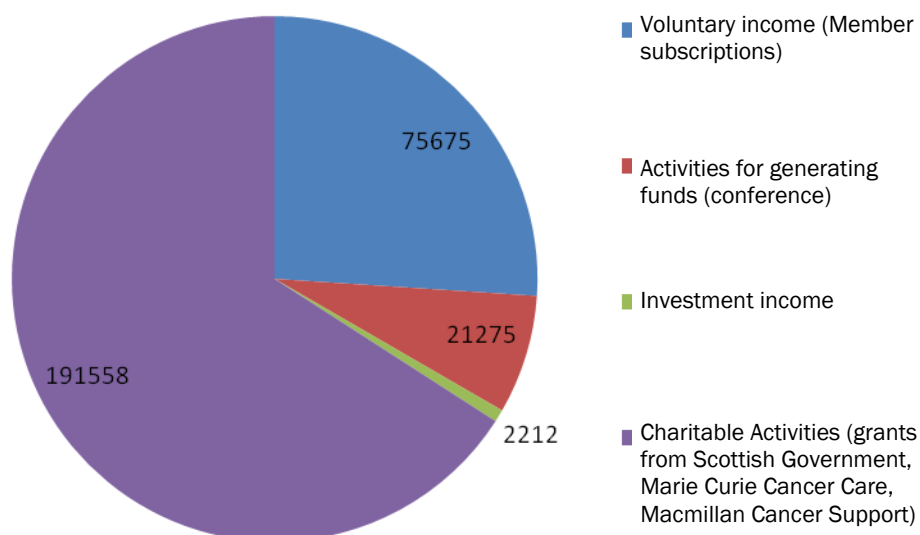
A major part of the Partnership's work is to identify and promote good practice in palliative care. The Partnership continued to publish UPDATE, a monthly e-bulletin which equips practitioners with the latest palliative care news and best practice. The Partnership published *Living and Dying Well with Dementia* a report unpicking the complex practicalities of meeting the palliative and end of life care needs of people with dementia and their families. In October the Partnership ran a very successful annual conference attended by over 220 people.

At the request of the Scottish Government the Partnership continued to provide administrative and project management support for the National Advisory Group for *Living and Dying Well*.

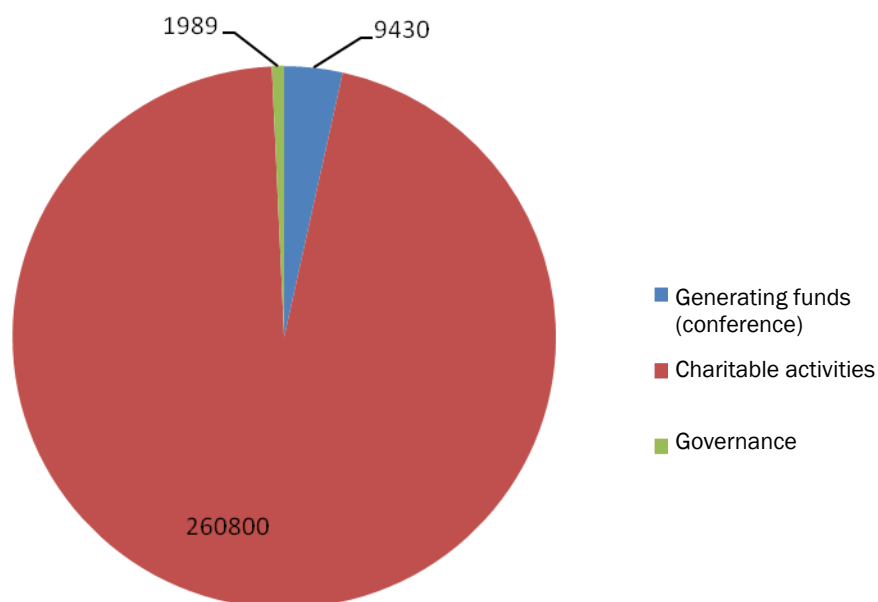
The Partnership also continued to provide the Secretariat for the Cross Party Group in the Scottish Parliament on Palliative Care.

Core income and expenditure account for the year ended 31 March 2012:

Incoming Resources £



Resources Expended £



Copies of the full audited accounts for the year, prepared in accordance with the Companies Act 1985, the Charities and Trustee Investment (Scotland) Act 2005 and the Charities Accounts (Scotland) Regulations 2006 by Chiene & Tait, Chartered Accountants and Registered Auditors, are available on request to the Scottish Partnership for Palliative Care.

Member Organisations at 31 March 2012



Office Bearers at 31 March 2012

Honorary President

Dr Derek Doyle OBE MB ChB FRCS FRCP FRCGP

Honorary Vice President

Professor Sir Kenneth Calman KCB MD FRCS FRSE

Chairman

Kate Lennon

(Co-opted)

Chief Executive
St Vincent's Hospice

Deputy Chairman

Margaret White

Assistant Director Hospices
Marie Curie Cancer Care

Honorary Treasurer

Dorothy McElroy

Chief Executive
Ardgowan Hospice

Council Members

Rhona Baillie

Chief Executive,
Prince and Princess of Wales Hospice

Elaine Burt

Head of Nursing, Rehabilitation & Assessment
Directorate, NHS Greater Glasgow and Clyde

Lorraine Dallas

Head of Scotland
Breast Cancer Care, Scotland

Linda Kerr

Nurse Specialist in Palliative Care
NHS Ayrshire and Arran

Dr Peter Kiehlmann

General Practitioner
NHS Grampian

Dr Gordon McLaren

Consultant in Public Health Medicine
NHS Fife

Dr Euan Paterson

General Practitioner
NHS Greater Glasgow and Clyde

Elaine Stevens

Lecturer in Cancer and Palliative Care
Independent Assoc. of Nurses in Palliative Care

Anne Willis

Hospice Manager
Marie Curie Hospice, Edinburgh

Observers

Rachael Dunk

Scottish Government Health Directorates

Patrick McAuley

Scottish Government Health Directorates

Eve Richardson

National Council for Palliative Care

Staff

Derek Blues

Policy Manager (Covering maternity leave)

Pauline Britton

Publications and Group Liaison Officer

Susan Diotaiuti

Executive Assistant/PA to Director

Claire Femister

Finance and Administration Manager

Mark Hazelwood

Director

Rebecca Patterson

Policy Manager (Maternity leave)



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 2011-2012 include: *'Paediatric Palliative Care in Scotland - How did we get here and where are we going?'*, *'Good Life, Good Death, Good Grief'* and *'A beginner's guide to successful palliative care research'*.

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 a new initiative of the Scottish Partnership for Palliative Care. The initiative is a Scottish alliance of organisations and individuals working together to promote community involvement in and raise public awareness of ways of dealing with death, dying and bereavement.



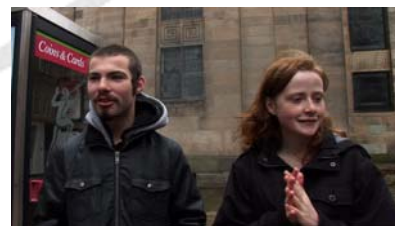
Scotland should be a society in which dealing with these issues in a healthy and constructive way is seen as part of ordinary everyday life and where members of the public and health and social care professionals and volunteers have awareness of death, dying, bereavement and loss, and the many ways in which communities and individuals can support each other.

If as individuals and society we are not open about these issues then it can make things worse. For example:

- People may die without writing a will, leaving all sorts of practical and financial complications for their family and friends
- If we are not able to acknowledge the reality of death and dying we may miss the opportunity to say 'goodbye' or 'I love you'
- If we cannot talk about death it makes it harder to acknowledge that there are limits to what medicine can achieve, and then people are more likely to undergo aggressive and futile medical interventions
- If health care professionals and the people they work with cannot be open and discuss these issues then it is more difficult to identify and put in place the care people would choose
- People sometimes tend to avoid those who are ill or bereaved for fear of 'upsetting them' by saying the wrong thing, which can leave people isolated.

The alliance is hosted and resourced by the Scottish Partnership for Palliative Care.

Join the alliance at: http://www.goodlifedeathgrief.org.uk/content/sign_up/



The stills above are taken from the DVD *'Twenty Takes on Death and Dying'* (commissioned by *Good Life, Good Death, Good Grief*) which can be viewed on its website at: http://www.goodlifedeathgrief.org.uk/content/20_takes/

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