

Scottish Partnership for Palliative Care

Annual Report

for the year ended 31 March 2008

Directors' Report for the year ended 31 March 2008

The Scottish Partnership for Palliative Care is the national umbrella and representative body for palliative care in Scotland. It seeks to ensure that high quality palliative care is available for all patients and families who need it on the basis of need rather than diagnosis.

Governance

The Scottish Partnership for Palliative Care is a charitable company limited by guarantee, and is registered as a Scottish charity with the Office of the Scottish Charity Regulator. The organisation is governed by its Memorandum and Articles of Association which define its sphere of activity and form its constitution. The Memorandum and Articles were adopted on 7 May 1991 and last amended on 8 September 2004.

The Partnership is a membership organisation, and criteria for membership are defined in the Memorandum and Articles of Association. At 31 March 2008 there were 56 member organisations, comprising NHS Boards, voluntary hospices, national charities and support organisations and professional associations. Each member organisation nominates a representative or representatives (four in the case of mainland NHS Boards and two in the case of island NHS Boards) to act as a formal link with the Partnership, attending meetings and exercising their organisation's vote(s) in Council elections and at Annual General Meetings.

The membership of the Partnership is divided into three national and three regional constituency groups. These groups elect representatives to the Partnership Council, which is the organisation's governing body. Each constituency group elects two representatives (except the West Regional Group which combines two previous groups and elects four) to act as Council members of the Partnership. Council members are elected for a period of three years, and may stand for re-election for a second period of three years. After six years in office they must stand down for a period of two years before being re-elected. Two additional Council members may be co-opted as required, but may serve no longer than six years. The Council may have up to up 14 elected members and an additional 2 co-options. Council members serve as Company Directors of the Scottish Partnership for Palliative Care, and function as its charity trustees. Council elects the Partnership's three office-bearers, Chairman, Deputy Chairman and Honorary Treasurer, on an annual basis. It also appoints an Honorary President and Vice-President(s) who may serve for up to six years.

Aims and objectives

The current charitable objects of the organisation are to promote, encourage, enhance, improve and extend the provision of palliative care services to people with life-threatening progressive conditions and their families and/or carers throughout Scotland. The long-term aims identified in the three-year workplan for 2005-2008 continued to be addressed throughout the year:

- to promote awareness and understanding of palliative care and its benefits to the public, patients and carers, health and social work professionals, planners and politicians
- to develop the capacity of palliative care services, whether in the NHS, independent sector, local authority or voluntary sectors by representing the need for adequate funding and availability of properly trained and qualified staff
- to promote equity of access to palliative care
- to improve access to palliative care for people with conditions other than cancer
- to promote palliative care in all settings including hospitals, primary care and independent care homes
- to encourage continuous quality improvement in palliative care at both generalist and specialist levels
- to work with bodies charged with monitoring quality of care (eg NHS QIS, Care Commission) to establish and maintain appropriate systems for the monitoring of palliative care in different settings
- to enable everyone involved in palliative care services in Scotland to share models of good practice and learn from each other's experience

- to ensure that the Partnership continues to be responsive to changes, including potential threats and opportunities, in the external environment
- to ensure that the Partnership's objectives and priorities remain relevant by maintaining dialogue and consultation as widely as possible with member organisations and others
- to ensure that the Scottish Partnership for Palliative Care has the funding, staff, management and resources to enable it to operate effectively in pursuit of the aims and objectives set out in its constitution.

These aims translated into specific objectives for the year which were met through a wide range of activities. The Partnership works with its constituency groups and working groups, with the Scottish Government and with appropriate local, regional and national bodies to influence policy and raise awareness of palliative care and to ensure the equitable and accessible provision of palliative care services to people in Scotland on the basis of need not diagnosis. It does this by initiating and sustaining a varied programme of meetings, events, consultation and dialogue, by maintaining an informed and effective communications network for its member organisations and by continuing to produce a variety of influential reports and publications.

Key Achievements

Chief among the achievements of the past year has been the Partnership's submission to, and subsequent acceptance by, the Scottish Government of its May 2007 report and recommendations *Palliative and end of life care in Scotland: the case for a cohesive approach*. The report was the culmination of work by a short-life working group, led by the Partnership chairman, and had been subject to consultation with member organisations. It recommended the mainstreaming of a number of evidence-based initiatives as a first step towards a national cohesive approach to the achievement of equitable access to high quality palliative and end of life care for patients and families across Scotland.

The Scottish Government's commitment to the adoption of these

recommendations was indicated in its national Action Plan for health and wellbeing, *Better Health, Better Care*, in December 2007. Subsequently, the first National Clinical Lead for Palliative Care was appointed with responsibility for implementation of the recommendations over a two year period and at the same time all NHS Boards were asked to identify an executive lead for palliative care to work with the National Clinical Lead in taking the work forward. These are exciting developments for palliative care and we look forward to continuing involvement in the identification of detailed strategies to ensure a national approach. The promised Scottish Government Action Plan for palliative and end of life care will be launched by the Cabinet Secretary for Health and Wellbeing at the Scottish Partnership for Palliative Care Annual Conference in October 2008.

Two further reports were published within the past 12 months. *A guide to using palliative care competence frameworks* was published with the support of NHS Education for Scotland at the end of March 2007, with the aim of assisting individuals and organisations in the use of palliative care competences to support recruitment, workforce planning, role design and career development. Informal feedback indicates that the report has been found useful.

A second major report, *Living and dying with advanced heart failure: a palliative care approach*, was published in March 2008 following widespread consultation and with the support of British Heart Foundation (Scotland) and the Scottish Government. The report draws attention to the unmet palliative care needs of many patients and families living with the effects of advanced heart failure and makes recommendations to address these. Again, the report has been well received and it is expected that its recommendations will be incorporated in the forthcoming revision of the Scottish Government CHD & Stroke strategy.

Review of activities

Regular meetings of the Partnership's **constituency groups** continued throughout the year, providing the opportunity to consult on proposed new developments, disseminate information and share good practice.

Regional groups focused on a range of issues which reflect the growing diversity of challenges and developments within palliative care. A number of groups discussed ways of implementing the recommendations of the Partnership's 2006 report *Joined up thinking ... Joined up care* on improving access to palliative care services for people with non-malignant conditions. Presentations included needs assessment for non-cancer palliative care, possible mechanisms for improving joint working between health and social care, support for palliative care in care homes, Alzheimer's Scotland 'Beyond Barriers' project on a palliative care approach to care for people with dementia living in care homes, the work of the Children's Hospice Association Scotland, the Marie Curie Delivering Choice Project in Tayside and developments in the Marie Curie Nursing Service. Close links were maintained with NOSCAN, the SCAN Palliative Care Reference Group and the West of Scotland Regional Managed Clinical Network for palliative care. The **Specialist Palliative Care Group** engaged with a variety of topics including the Audit Scotland review of palliative care

services, quality of life assessment and palliative care research, bereavement services, palliative care and dementia, and the implications of Modernising Medical Careers on workforce planning in specialist palliative care. Members of the Group also formed a short-life working group to work with the Scottish Ambulance Service to produce new DNAR and palliative care algorithms and guidelines for ambulance crews across Scotland.

The **National Charities Group** continued to benefit from the sharing of information and expertise made possible by the current even balance of membership between charities representing cancer and those representing other conditions. Presentations and discussions included the work of British Heart Foundation Scotland, CLIC Sargent, Alzheimer's Scotland, the Long Term Conditions Alliance Scotland (LTCAS), the Neurological Alliance of Scotland, the Youth Cancer Forum Scotland, the Children's Hospice Association Scotland, and Marie Curie Cancer Care.

The **Scottish Hospices Forum** sustained a demanding business agenda relating mainly to funding requirements and to the regulatory and quality assurance frameworks within which voluntary hospices operate. Close working relationships were enjoyed with the Care Commission and with Help the Hospices, both of which were represented at meetings. Forum members worked with representatives of the Scottish Government Information and Statistics Division (ISD) on data collection issues, and an ISD Hospice Awareness Day was held in June 2007. There was liaison with NHS Education for Scotland regarding appropriate training for hospice Accountable Officers and representation from the Forum on the NHS Quality Improvement Scotland Joint Clinical Governance and Risk Managers Network and on the Scottish Government group set up to take forward the implementation in Scotland of the policy principles of appraisal in the voluntary hospice sector set out in the UK Government White Paper *Trust, Assurance and Safety – The Regulation of Health Professionals in the 21st Century*.

Throughout the year, the Partnership continued to respond to widespread requests for **information and support** from individuals and organisations. Member organisations were consulted and responses submitted to Scottish Government consultations such as *Better Health, Better Care: a discussion document*, and *Better Cancer Care: a discussion*. An informal consultation was carried out to assess views on the new model for community nursing outlined in *Visible, Accessible and Integrated Care* and its possible implications for palliative care in the community and the results communicated to the Nursing Review Programme Board. The Partnership commented on the review of guidance on NHS Continuing Care, and at the request of the Scottish Parliament Public Petition's Committee provided comments on Public Petition PE1031: Assisted suicide (Opposition to Legislation). The Partnership was also represented on the Project Advisory Group for Audit Scotland's current review of palliative care services in Scotland.

The **Annual Conference** in August 2007 *Active and holistic? .. planning for palliative care in 2027* challenged delegates with a glimpse of possible futures for palliative care and included a look at the service implications of demographic changes, joint working between health and social care, and provision of

palliative care in a variety of settings including care homes and community hospitals. The programme also highlighted the emerging importance of self-care and self-management and of remote monitoring and e-health, and the event closed with an impassioned plea by Hon President Dr Derek Doyle that the core skills and values of palliative care in recognising the unique complexity of every human being and of simply 'being there' at times of suffering should not be lost in current trends and developments within medicine.

The Partnership continued to provide the secretariat for the **Cross Party Group in the Scottish Parliament on Palliative Care**. Office bearers were elected at the AGM in June 2007, and the Cross Party Group (CPG) was successfully reconstituted and met for the first time in the new parliamentary session in December 2007. As well as keeping abreast of current issues such as prescription charges, Modernising Medical Careers, the Community Nursing Review and the Public Petition on Assisted Suicide (Opposition to Legislation) submitted to the Scottish Parliament in September 2007, the CPG heard and discussed presentations on the Partnership's recommendations for palliative and end of life care in Scotland, the work of British Lung Foundation Scotland and the unmet palliative care needs of people with chronic obstructive pulmonary disease (COPD), the results of a Scotland-wide service mapping and prevalence project on chronic oedema / lymphoedema, and the General Medical Council Review of the 2002 publication *Withholding and Withdrawing Life-prolonging Treatments: Good Practice in Decision-making*.

Future plans

A new outline **three-year workplan** for 2008-2011 was approved by Council in March 2008. This will take forward a number of existing workstreams as well as introduce new ones. Activities are based on the key elements of the organisation's aims as identified in the strategic review undertaken during 2007-2008:

- promoting equitable access to high quality palliative care for all
- influencing national palliative care strategy
- providing leadership
- facilitating co-ordination across boundaries to promote consistency of approach
- promoting and sharing good practice.

As a result of the governance and strategic review commenced by the Partnership Council during 2007-2008, a proposal to update the company objects to better reflect its range of activities and influence was agreed by Council in March 2008 for consultation by the membership and possible submission to the AGM in 2008-2009.

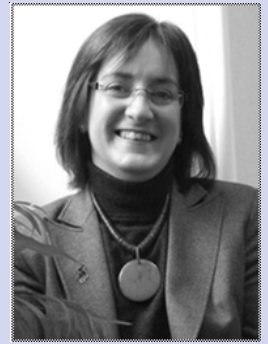
As I reflect on the 12 months covered by this report I am excited and empowered by the context in which we find ourselves and the opportunities open to us to shape and deliver effective palliative care across Scotland. I feel both privileged and humbled to have the opportunity to be so intimately involved in the development of palliative care in Scotland. Over the last year the Partnership has been noticeably influential in successfully supporting the strategic development of palliative and end of life care, demonstrated clearly by the commitments outlined in the Scottish Government Action Plan for Health and Wellbeing, Better Health, Better Care in December 2007. In addition, Scotland now also has in Dr Elizabeth Ireland its first national clinical lead for palliative care and plans for an executive lead for palliative care in each of the NHS Boards. During 2007 the Partnership has been working alongside the Audit Scotland review team to facilitate communication with the relevant agencies and to ensure the review team had access to current and planned developments in palliative care. I am clear that the Partnership has indeed encouraged and supported the creation of conditions which will facilitate the future delivery of high quality palliative and likely complex end of life care, based on clinical need not diagnosis, across all care settings, across Scotland. This new context offers those of us involved in service delivery a genuine opportunity to further enrich our services to ensure they will meet the future needs of the many and varied communities that we serve.

The Partnership continues to support and encourage the development of palliative care services for conditions other than cancer and a real success for 2007-2008 was the joint publication with the British Heart Foundation Scotland of the long-awaited *Living and Dying with Advanced Heart Failure: a palliative care approach*. A successful partnership indeed!

In recognition of the evolving role of the Scottish Partnership for Palliative Care, Council agreed during 2007 that the time was right to undertake a review of its corporate governance. This review, currently ongoing, addresses the role, function and operation of the organisation, and the checks and balances, structures and processes necessary for appropriate decision making and accountability. Its overall aim is to ensure that the Partnership is and remains an organisation "fit for purpose". The first stage is the current member consultation on the proposed amendment of the Company Objects.

2008 is proving to be another year of challenge, new developments and building for the future. During the coming year the Partnership has an ambitious workplan that includes supporting the development and implementation of the first national palliative care action plan for Scotland, publishing guidance on undertaking research in palliative care, and conducting an impact assessment of its 2006 national practice statements for general palliative care in adult care homes. As ever the Partnership will continue to engage with its members to ensure that we continue to support the development of palliative care across Scotland.

The Partnership, guided by the visionary leadership of Pat Wallace, has a highly regarded and much appreciated staff team, who deliver exceptional results and consistently demonstrate their willingness to respond to changes in the context within which we all operate. Together with the equally hard-working and committed Members of Council, they help to ensure that the Partnership remains an effective force for change in palliative care in Scotland.



Maria McGill, Chairman

Scottish Partnership for Palliative Care

Member Organisations at 31 March 2008

NHS Boards

NHS Ayrshire & Arran
NHS Borders
NHS Dumfries & Galloway
NHS Fife
NHS Forth Valley
NHS Grampian
NHS Greater Glasgow and Clyde
NHS Highland
NHS Lanarkshire
NHS Lothian
NHS Orkney
NHS Shetland
NHS Tayside
NHS Western Isles

Voluntary Hospices

Accord Hospice
Ardgowan Hospice
Bethesda Hospice
Children's Hospice Association Scotland
Highland Hospice
Marie Curie Hospice, Edinburgh
Marie Curie Hospice, Glasgow
Prince & Princess of Wales Hospice
St Andrew's Hospice
St Columba's Hospice
St Margaret of Scotland Hospice
St Vincent's Hospice
Strathcarron Hospice
The Ayrshire Hospice

National Charities

Alzheimer Scotland - Action on Dementia
Breast Cancer Care Scotland
British Heart Foundation
British Lung Foundation
Cancerbackup Scotland
Chest, Heart and Stroke, Scotland
CLIC (Cancer & Leukaemia in Children) Sargent
Macmillan Cancer Support
Maggie's Cancer Caring Centres
Marie Curie Cancer Care
Multiple Sclerosis Society Scotland
Pain Association Scotland
Parkinson's Disease Society
Roy Castle Lung Cancer Foundation
Scottish Conference of Cancer Support Groups
Scottish Huntington's Association
Scottish Kidney Federation
Scottish Motor Neurone Disease Association
Sue Ryder Care
Tak Tent Cancer Support Scotland

Professional Associations

Association for Palliative Medicine
Association of Bereavement Service Co-ordinators
Association of Hospice & Palliative Care Chaplains
Association of Palliative Care Social Workers
Nurses Managing Hospices & Specialist Palliative Care Services
RCN Palliative Nursing Group
Scottish Palliative Care Pharmacists' Association

Support Organisations

Cancer Link Aberdeen and North (CLAN)

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The publication of Audit Scotland's review of palliative care services in July 2008 and the launch of the forthcoming Scottish Government Action Plan for palliative and end of life care in October 2008 are both expected to influence the Partnership's detailed activities in the coming months.

Financial review

The Partnership recorded a net surplus for the year of £6,683. Unrestricted income of £217,531 was generated mainly from grant funding and member subscriptions and Council gratefully records its appreciation to the Scottish Government Health Directorates, Marie Curie Cancer Care and Macmillan Cancer Support for grants received for core administration costs. Employment costs formed the most significant element of the £210,848 of unrestricted expenditure. Council also records its thanks to Marie Curie Cancer Care and to the British Heart Foundation, Scotland for restricted funds of £3,390 and £3,000 respectively received during the year.

Key Partners

The Partnership's effectiveness as an organisation and its success in delivering its objectives depends largely on the contribution of its member organisations and other key partners. We value highly our relationships with our members and with national bodies such as the Scottish Government Health Directorates, NHS Education for Scotland, NHS Quality Improvement Scotland, the Scottish Ambulance Service, the Care Commission, Marie Curie Cancer Care, Macmillan Cancer Support, Help the Hospices and the National Council for Palliative Care. We would like to extend our thanks to all those individuals and organisations who have worked with us over the past year, contributing to constituency groups and working groups, responding to consultations, providing information and advice, and generally supporting our work through sharing generously of their time, effort and expertise.

Scottish Partnership for Palliative Care

Core income and expenditure account for the year ended 31 March 2008

Honorary President

Dr Derek Doyle OBE MB ChB FRCS FRCP FRCGP

Honorary Vice President

Professor Sir Kenneth Calman KCB MD FRCS FRSE

Council (as at 31 March 2008)

Maria McGill Chairman	Chief Executive, Highland Hospice
Vacancy Deputy Chairman	
Craig Stockton Honorary Treasurer	Chief Executive, Scottish Motor Neurone Disease Association
Maureen Black	Senior Development Officer, Macmillan Cancer Support
Dr David Carroll	Associate Specialist in Palliative Care / GP Facilitator, NHS Grampian
Rev Stuart Coates	Chaplain, Association of Hospice and Palliative Care Chaplains
Anne Willis	Hospice Manager, Marie Curie Hospice, Edinburgh
Vicky Freeman	Cancer Services Programme Manager, NHS Dumfries & Galloway
Tom Gault	Chief Executive, St Andrew's Hospice
Trudy Lafferty	Matron, St Vincent's Hospice
Kate Lennon	Macmillan Nurse Consultant in Palliative Care, NHS Greater Glasgow & Clyde
Dorothy McElroy	Chief Executive, Ardgowan Hospice
Dr Clive Preston	Consultant in Palliative Medicine, NHS Fife
Dr Chris Sugden	Consultant in Palliative Medicine, St Andrew's Hospice
Professor John Welsh	Professor of Palliative Medicine, NHS Greater Glasgow and Clyde

Assessors

Dr Jennifer Armstrong	Scottish Executive Health Directorates
Colin Brown	Scottish Executive Health Directorates

Observer

Eve Richardson	Chief Executive, National Council for Palliative Care
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Staff

Patricia Wallace	Director
Pauline Britton	Publications & Group Liaison Officer
Susan Diotaiuti	Executive Assistant / PA to the Director
Claire Femister	Finance & Office Administrator
Rebecca Patterson	Policy Manager

	31.03.07	31.03.08
	£	£
Income		
Grants for core administration costs:		
- Scottish Government Health Directorates	83,000	87,000
- Help the Hospices	0	0
- Macmillan Cancer Support	20,000	20,600
- Marie Curie Cancer Care	20,000	20,500
Members subscriptions	64,538	69,196
Interest on deposit	4,604	5,315
Donations	0	0
Annual conference	13,800	14,920
	<u>205,942</u>	<u>217,531</u>
Expenditure		
Salaries, NI and pensions	147,323	161,133
Rent	9,500	9,500
Water rates	672	687
Insurance	1,348	1,368
Light and heat	2,628	2,650
Maintenance and repairs	6,727	5,263
Cleaning	2,552	1,844
Stationery	2,819	4,012
Printing and publications	4,009	8,308
Postage	2,426	2,671
Telephone	1,566	1,512
Travel and meetings expenses	5,063	4,586
Annual conference	5,731	3,981
Audit fee	995	1,000
Professional fees	4,776	0
Recruitment	1,862	0
Training and development	1,639	0
Office equipment	529	0
General expenses	280	554
Depreciation of office equipment	669	1,779
	<u>203,114</u>	<u>210,848</u>
Surplus / (deficit) for the year	2,828	6,683
Accumulated surplus brought forward	90,333	93,161
	<u>93,161</u>	<u>99,844</u>

Restricted funds income and expenditure account for the year ended 31 March 2008

	2007	2008
	£	£
Big Lottery Fund Project		
Balance from last year	44,918	0
Grant received during the year	59,383	0
Expenditure during the year	(104,301)	0
Scottish Executive <i>(publication of Making Good Care Better)</i>		
Grant received during the year	20,111	0
Expenditure during the year	(20,111)	0
Marie Curie Cancer Care <i>(reprint of Making Good Care Better)</i>		
Grant received during the year	-	3,390
Expenditure during the year	-	(3,390)
British Heart Foundation (Scotland) <i>(publication of Living and Dying with advanced heart failure)</i>		
Grant received during the year	-	3,000
Expenditure during the year	-	(3,000)

Copies of the full audited accounts for the year, prepared in accordance with the Companies Act 1985 by Messrs Dalgliesh & Tullo, Registered Auditors and Chartered Accountants, are available on request to the Scottish Partnership for Palliative Care.