

A large, thick purple arc that forms a partial circle, framing the central text.

**Scottish Partnership  
for Palliative Care**

***Annual Report***

*for the year ended 31 March 2007*

# Directors' Report for the year ended 31 March 2007

*The Scottish Partnership for Palliative Care is the national umbrella and representative body for palliative care in Scotland. As such, it provides a unique 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.*

## Aims and objectives

The charitable objects of the Scottish Partnership for Palliative Care (the Partnership) 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. While the objects remain unchanged, the Partnership constantly reviews how best to achieve them as we seek year on year to maintain a balance between being proactive in pursuit of our aims and objectives and being reactive to the pressures and realities of the unfolding health, social, financial and demographic environment.

The Partnership operates to a three-year work-plan agreed and monitored by its governing Council. This identifies both long-term aims relating to the charitable objects, and specific annual objectives. Long term aims identified in the three-year work-plan for 2005-2008 are as follows:

- 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, such as NHS Quality Improvement Scotland and the 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.

The past year has seen a particularly successful range of activities and achievements, outlined below, during which the year's objectives were largely met and new initiatives identified.

## Key Achievements

Key achievements during the year have included publication and dissemination of two influential reports.

***Making good care better: National practice statements for general palliative care in adult care homes in Scotland** (May 2006), published jointly with the Scottish Executive, launched a series of national practice statements to be used by care homes alongside the National Care Standards and regarded as good practice by the Care Commission in their inspections of adult care homes. They have been well-received, and, in time, are expected to contribute to improved standards of general palliative care in care homes across Scotland. Increased palliative care education activity involving the sector has already been noted.*

*Joined up thinking  
Joined up care...  
Report of the Scottish  
Partnership for  
Palliative Care Big  
Lottery Fund project:*



*'Increasing access to palliative care for people with life-threatening conditions other than cancer' was launched at the Partnership's Annual Conference in November 2006 and marked the successful completion of its three-year Big Lottery Fund project on improving access to palliative care for people with progressive non-malignant conditions. The report summarises the findings of extensive consultation throughout Scotland into the palliative care needs of people with conditions other than cancer, the barriers they currently experience in accessing appropriate palliative care, and ways in which these barriers may be overcome. It identifies increased collaboration and joint working as a key way forward, and proposes a model of care which emphasises a need for the skills of generalists and specialists alike. The publication has been universally welcomed and is already being used as a strategic planning tool. It makes a number of recommendations and offers practical guidance to NHS Boards and local authorities and to health and social care professionals.*

Both of these pieces of work were also presented during the year to meetings of the **Cross Party Group in the Scottish Parliament on Palliative Care** for which the Partnership continues to provide the secretariat. The **Annual Conference** itself was a highlight of the year, securing the participation and support of the Deputy Health Minister and the Chief Medical Officer, and attracting 50% more delegates than previously, many from sectors not usually represented.

## Governance

The governing body of the Partnership is the **Council**, whose members are elected from the organisation's constituent groups. The organisation is a charitable company limited by guarantee, and is registered as a Scottish charity with the Office of the Scottish Charity Regulator. Council Members serve as Company Directors of the Scottish Partnership for Palliative Care, and function as its charity trustees. The organisation is governed by its Memorandum and Articles of Association, which define its sphere of

activity and together 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 2007 there were 55 member organisations, comprising NHS Boards, voluntary hospices, national charities and support organisations and professional associations (see page 5). 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 and to exercise their organisation's vote(s) in Council elections and at Annual General Meetings.

## Review of activities

The Partnership continues to sustain a wide range of activities. It works with its constituency groups and working groups, and with the Scottish Executive and appropriate local, regional and national bodies to 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 producing a growing range of reports and publications.

## Council

Council had a full programme of quarterly meetings during the year, receiving and approving financial monitoring reports and reports of short-life working groups and steering groups, and reviewing and approving the policies, work-plans and practices of the Partnership.

## Constituency groups

The activities of its regional and national groups and the communications network they provide remain the constitutional and practical mechanism by which the Partnership achieves many of its objectives. The three regional groups continue to work closely with regional cancer and palliative care networks, with different practical arrangements pertaining in each area, while the three national groups maintain strong working links with a range of external organisations. In addition to the scheduled programme of meetings all groups participate in frequent consultation exercises, initiated or facilitated by the Partnership, and receive ongoing communication updates regarding local, regional and national palliative care issues and events.

The **North Regional Group** holds its meetings via a total of up to six video-conference sites linking mainland and island NHS Board areas. It works closely with the North of Scotland Cancer Network (NOSCAN), and during the year jointly confirmed the decision that it should continue to function as the sole regional forum for palliative care in the north of Scotland. The Group discussed and heard presentations on a range of local, regional and national issues including future requirements for Highland Hospice, the Marie Curie Delivering Choice Tayside Project, the National Generic Clinical System, the Gold Standards Framework Scotland, the pan-Lothian Do Not Attempt Resuscitation (DNAR) policy, the Children's Hospice Association Scotland and self-care and self-management in cancer.

The **South East Regional Group** maintains close links with the South East Scotland Cancer Network Palliative Care Reference Group, holding consecutive meetings on the same day and maintaining joint representation on each. This group's agenda also included the pan-Lothian DNAR policy and the Marie Curie Delivering Choice Tayside Project, as well as the implications for palliative care and home care of the Scottish Executive Social Work Review for the 21st century and the future strategic direction of Macmillan Cancer Support.

In the West of Scotland, a review and restructuring of the West of Scotland Managed Clinical Network for Palliative Care led to a revision of the existing arrangement for joint meetings of the MCN steering group and the Partnership's **West Regional Group**, with separate meetings re-established from January 2007. The Regional Group heard a presentation on the pan-Lothian (DNAR) policy and Scottish Ambulance Service plans for its use throughout Scotland at its first separate meeting, and decided to focus its interest subsequently on the progress of work on the non-cancer agenda in the West of Scotland.

The **Specialist Palliative Care Group** maintained a very full programme of activities and liaison with external bodies throughout the year. Members worked closely with the Scottish Ambulance Service regarding patient transfer issues and palliative care training for ambulance crews, as well as the development of clinical standards in cancer and palliative care and national guidelines on palliative care and DNAR. There was consultation with the Scottish Audit of Surgical Mortality on the palliative care component of its annual survey, and the Group made successful representation to the Scottish Executive for inclusion of an amendment regarding disposal of drugs from the home in the new edition of its *What to do after a death in Scotland* publication. A recommendation was submitted to the Chief Medical Officer (CMO) for the development of national guidance on disposal of drugs following a survey of Community Pharmacists into current practice which highlighted existing confusion and lack of consistency, and the Group also expressed its concerns to the CMO regarding implications of the current Modernising Medical Careers initiative for the future training of doctors in palliative care.

The **Scottish Hospices Forum** continued to work closely with the Care Commission on a range of regulation and quality issues, as well as with other bodies such as the Scottish Ambulance Service, NHS Quality Improvement Scotland, Help the Hospices and ISD. The Forum also raised concerns regarding the palliative care workforce planning implication of Modernising Medical Careers and inconsistencies in available funding for the Additional Cost of Teaching, and continued to discuss issues around the Hospice Computerised Administration System and alternative data collection systems. Extra meetings were held during the year to address a range of specific issues and an additional funding survey was carried out to ascertain progress in negotiations between hospices and NHS Boards regarding proposed full implementation in 2007-2008 of the 50-50 funding agreement.

Membership of the **National Charities Group** expanded considerably over the year with the addition to its ranks of Alzheimer Scotland – Action on Dementia, British Lung Foundation Scotland, Chest, Heart and Stroke Scotland, Maggie's Cancer Caring Centres Scotland, Scottish Kidney

Federation and Sue Ryder Care. An active programme of discussion and information-sharing among new and existing members took place. On the advice of the Group and with the agreement of Council, the Scottish Partnership for Palliative Care became, during the year, an Associate Member of the Long Term Conditions Alliance Scotland and maintained links with the Neurological Alliance of Scotland.

### Annual general meeting

This year's Annual General Meeting was held as a half-day event in December 2006, and included an address by Honorary Vice-President Professor Sir Kenneth Calman KCB. Following the business proceedings, Honorary President Dr Derek Doyle OBE chaired a brief and informative forum on issues in palliative care research.

### Information provision

Throughout the year the Partnership continued to be a source of information on palliative care issues, responding to a range of queries and requests from individuals and organisations at local, national and international level. Permission was granted to researchers in England and New Zealand to replicate the Partnership's 2003 survey into public attitudes towards palliative care. A survey into the existence or not of a so-called 'Shipman effect' on palliative care prescribing in Scotland was carried out at the request of the CMO. Results indicated little evidence of such an effect, but widespread concerns at the possible effects on prescribing practice of recent changes in out of hours arrangements were reported. Assistance was also provided to ISD in ensuring the participation of palliative care patients and carers in the Scottish Parliament's public consultation into prescription charges. A request was received from the Public Petitions Committee of the Scottish Parliament for comments on a petition and Committee discussion on legislation against physician assisted suicide, and the Partnership will be consulting with its members to frame a suitable response.

### Future plans

Work continued throughout the year towards publications on **palliative care competence frameworks** and on **palliative care and advanced heart failure**, both of which are scheduled for publication during 2007-2008, and on a consultation and report with recommendations to the Scottish Executive on **the case for a cohesive approach to palliative and end of life care in Scotland**, to be submitted in May 2007. A palliative care research forum held

*Continued on page 5*

As I reflect on the 12 months covered by this report it has become clear the Partnership has experienced yet another year of tremendous success and achievement. I value this opportunity, as we look forward to the next year, to share my thoughts and hopes with you.

It is a genuine privilege to follow in Professor Frank Clark's footsteps to serve the Partnership and the membership as Chairman. Frank's inexorable energy, vision and commitment were a real inspiration to all of us and his wise counsel was appreciated by many. As for me, I am excited and energised by the context in which we find ourselves and the opportunities available to us to shape and deliver effective palliative care across Scotland.

The current challenges in palliative care have provided context and focus to the work of the Partnership over the year:

### Increasing access to palliative care for people with non-malignant disease:

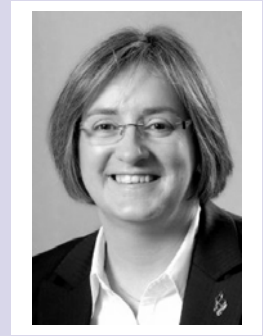
The report from the Partnership's Big Lottery Fund Project, launched at our annual conference, has been warmly received by those involved in policy making, clinicians and practitioners and most importantly by the service users involved in shaping the direction and content of the report. At the conference the Chief Medical Officer Harry Burns said 'This report offers a profound challenge to conventional thinking and requires inter-agency collaboration of a high order'. This landmark report is considered to be so important that the Partnership will over the next 12 months be reviewing the ways in which NHS Boards, Community Health Partnerships, local authorities and individual practitioners are using it to change and develop services.

**Provision of palliative care across multiple settings:** The launch of *Making good care better* by Jacqui Roberts, Chief Executive of the Care Commission, at a meeting of the Cross Party Group in the Scottish Parliament on Palliative Care demonstrates our commitment to redressing the inequities that exist in the provision of palliative care.

**Provision of quality palliative care education to meet the needs of the workforce:** The soon to be published document *A guide to using palliative care competence frameworks* is yet another practical example of the Partnership's commitment to seeking and providing the relevant expertise that will support the palliative care community.

As we prepare ourselves for the future it is clear that the need continues to be great for access to palliative care with non-malignant disease, for more equitable service delivery across all settings, for even closer working between the NHS, voluntary organisations and local authorities, for continued research and finally for sustainable funding for the vital services we all provide. Our responsibility is to create the conditions in which this can happen and facilitate the delivery of high quality palliative and end of life care across all care settings across Scotland. I believe the time is right to achieve this, with many people already recognising the imperative to deliver and already changing practice.

Every successful organisation needs good leadership and we certainly have that in Pat Wallace, our Director, who along with the rest of the dedicated team ensures the highest standards in everything the Partnership does. The Partnership is fortunate in its strengths and is inspired by the challenges and opportunities of the future.



*Maria McGill, Chairman*

# Scottish Partnership for Palliative Care Member Organisations at 31 March 2007

## 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 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)

*Continued from page 4*

alongside the annual general meeting in December 2006 identified the need for a future publication to provide guidance to those wishing to undertake **research in palliative care**, and it was subsequently agreed that a short-life working group would be set up to take this forward later in 2007.

The palliative care study to be undertaken by Audit Scotland during 2007-2008 is also expected to contribute to future work plans and strategic directions.

## Financial review

The Partnership recorded a net surplus of £2,828 for the year ending 31 March 2007. Unrestricted income of £205,942 was generated mainly from grant funding and member subscriptions. The nature of the Partnership's activity means that employment costs formed the most significant element of the £203,114 of unrestricted expenditure. Council gratefully records its appreciation to the Scottish Executive, Marie Curie Cancer Care and Macmillan Cancer Support for grants received for core administration costs and to the Big Lottery Fund and the Scottish Executive for restricted funds of £59,383 and £20,111 respectively received during the year. Core and restricted income and expenditure accounts for the year appear on page 6.

## Key partners

The Partnership would be unable to meet its objectives without the ongoing support of the key individuals and organisations with whom it works. Sincere thanks are expressed to all those who have given of their time and effort to participating in working groups, responding to consultations and queries, engaging in dialogue and sharing with us their knowledge and expertise. We acknowledge gratefully the active support of all of our member organisations and others, such as the Care Commission, Help the Hospices, Macmillan Cancer Support, Marie Curie Cancer Care, NHS Education for Scotland, NHS Quality Improvement Scotland, the National Council for Palliative Care and the Scottish Executive, and look forward to working with you all in the future.

# Scottish Partnership for Palliative Care

## Core income and expenditure account for the year ended 31 March 2007

### 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 2007)

Maria McGill Chairman	Chief Executive, Highland Hospice
Dr Elizabeth Ireland Deputy Chairman	Lead Clinician and General Practitioner, NHS Forth Valley
Craig Stockton Honourary 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
Margaret Dunbar	Director of Nursing, St Columba's Hospice
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 Catriona Ross	Consultant in Palliative Medicine, St Andrew's Hospice
Professor John Welsh	Professor of Palliative Medicine, NHS Greater Glasgow and Clyde

### Assessors

Nick Brown	Scottish Executive Health Department
Fiona Warner	Scottish Executive Health Department

### 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 and PA to the Director
Claire Femister	Finance & Office Administrator
Rebecca Patterson	Policy Manager

	31.03.06	31.03.07
	£	£
<b>Income</b>		
Grants for core administration costs:		
- Scottish Executive Health Department	80,000	83,000
- Help the Hospices	5,000	0
- Macmillan Cancer Support	19,200	20,000
- Marie Curie Cancer Care	18,540	20,000
Members subscriptions	62,486	64,538
Interest on deposit	4,619	4,604
Donations	10,498	0
Annual conference	16,650	13,800
	<u>216,993</u>	<u>205,942</u>
<b>Expenditure</b>		
Salaries, NI and pensions	151,880	147,323
Rent	9,500	9,500
Water rates	1,313	672
Insurance	1,943	1,348
Light and heat	2,917	2,628
Maintenance and repairs	3,731	6,727
Cleaning	2,213	2,552
Stationery	(785)	2,819
Printing and publications	6,109	4,009
Postage	2,513	2,426
Telephone	1,749	1,566
Travel and meetings expenses	2,740	5,063
Annual conference	10,534	5,731
Audit fee	950	995
Professional fees	18,675	4,776
Recruitment	3,116	1,862
Training and development	0	1,639
Office equipment	0	529
General expenses	0	280
Depreciation of office equipment	3,083	669
	<u>222,181</u>	<u>203,114</u>
Surplus / (deficit) for the year	(5,188)	2,828
Accumulated surplus brought forward	95,521	90,333
	<u>90,333</u>	<u>93,161</u>

## Restricted funds income and expenditure account for the year ended 31 March 2007

<b>Big Lottery Fund Project</b>	2006	2007
	£	£
Balance from last year	41,643	44,918
Grant received during the year	82,090	59,383
Expenditure during the year	123,733	104,301
	(78,815)	(104,301)
	<u>44,918</u>	<u>0</u>
<b>Scottish Executive (publication of Making Good Care Better)</b>	2006	2007
	£	£
Grant received during the year	-	20,111
Expenditure during the year	-	(20,111)
	<u>-</u>	<u>0</u>

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.