

Scottish Partnership for Palliative Care

Annual Report

for the year ended 31 March 2009

Directors' Report for the year ended 31 March 2009

The Scottish Partnership for Palliative Care is an umbrella and representative organisation which, through a collaborative approach, supports and contributes to the development and strategic direction of palliative care in Scotland. The Company's objects are to promote equitable access throughout Scotland to high quality palliative care for all patients and families on the basis of need not 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 at the 17th Annual General Meeting on 2 October 2008, when the amended company objects above were unanimously approved.

Strategic and governance review

This represented the culmination of the first stage of a wide-ranging and ongoing strategic and governance review initiated by the Partnership Council, its governing body, in 2007. This has involved a major overhaul of all aspects of our structures, policies and practices and was designed to ensure that the organisation remains not only fit for purpose and compliant with current legislation, but able, where appropriate and in collaboration with its member organisations, to undertake a leading role in the development of national palliative care strategy.

Work on this review has continued during 2008-2009, focusing on membership and governance structures and processes. Member organisations were consulted early in 2009 on a range of proposed amendments to the Articles of Association, among them a proposal to introduce a category of Associate Membership for a wider range of organisations than those with whom we are currently formally engaged. This, along with other amendments designed to update and streamline governance practices, will be put to members at the AGM on 30 September 2009 and will, in the view of Council, ensure that the Partnership is appropriately structured and positioned to take forward its vision of equitable palliative care for all who need it across all care settings and all conditions.

Membership and governance structures

At 31 March 2009 there were 54 member organisations, comprising NHS Boards, voluntary hospices, national charities and support organisations and professional associations. Each member organisation nominates a representative or representatives as defined in the Articles of Association to act as a formal link with the Partnership, attending meetings, taking part in consultations and exercising their organisation's vote(s) in Council elections and at Annual General Meetings.

Member organisations are represented on three national and three regional constituency groups, each of which elects two of its members (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. 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 Treasurer, from its own Members. It also appoints appropriate individuals from the world of palliative care to serve as Honorary President and Vice-President as required.

Risk Assessment

One of the Council's key duties in strategic and governance terms is the assessment of current and future risk to the organisation. Council responded swiftly to news of the forthcoming retirement of the current Director in December 2009 both by setting up and implementing a robust recruitment strategy and schedule and by reviewing the terms of office of the current office-bearers. To ensure appropriate handover and continuity arrangements, Council agreed unanimously that the post

should be advertised in May 2009 and that the current Chairman, who was due to stand down, should be co-opted for a further year in the first instance.

Aims and objectives

The strategic review identified the following aims for the Scottish Partnership for Palliative Care:

- promote equitable access to high quality palliative care for all
- influence national palliative care strategy
- provide leadership for palliative care planners and practitioners
- promote consistency of approach by facilitating co-ordination across organisational boundaries
- promote and share good practice
- ensure that the Scottish Partnership for Palliative Care remains an organisation fit for purpose.

These were reflected in the specific objectives of the three-year outline work plan for 2008-2011 and in the detailed work plan for 2008-2009, approved by the Partnership Council in March 2008 and June 2008 respectively. Council reviews the Partnership's performance against the workplans and sets new targets annually.

Key Achievements

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,



*Nicola Sturgeon, Cabinet Secretary
for Health and Wellbeing*

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 ensure the equitable and accessible provision of palliative care services to patients and families 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. There have been a number of key achievements throughout the year.

Action Plan: *Living and Dying Well*

The highlight of the 2008-2009 year has undoubtedly been the publication and launch by the Cabinet Secretary for Health and Wellbeing at the Scottish Partnership for Palliative Care Annual Conference in October 2008 of *Living and Dying Well, a national action plan for palliative and end of life care in Scotland*. This action plan is the first of its kind in Scotland and is the culmination of the Scottish Government's commitment, stated in the December 2007 *Better Health, Better Care: Action Plan*, to implement the recommendations put forward by the Scottish Partnership for Palliative Care in its May 2007 report, *Palliative and end of life care in Scotland: the case for a cohesive approach*.

This represents an exciting and positive step towards the development of equitable, consistent and accessible high quality palliative and end of life care services across Scotland, and provides evidence both of the Partnership's growing influence and success, and of the strength of its collaborative approach. At the end of March 2009, all NHS Boards have in place detailed development plans for the implementation of *Living and Dying Well*, and palliative care Executive Leads in each Board area will be working closely with Dr Elizabeth Ireland, the National Clinical Lead for Palliative Care to take the work forward.

Annual conference

Apart from providing a platform for the launch of *Living and Dying Well*, the Partnership's 2008 Annual Conference *Palliative Care: daring to be different* offered informative and challenging presentations from a range of speakers under the much valued and inspirational chairmanship of our Honorary President Dr Derek Doyle OBE. Dr Harvey Max Chochinov, Canada Research Chair in Palliative Care, Director of the Manitoba Palliative Care Research Unit and Distinguished Professor, Department of Psychiatry, University of Manitoba, became our first international guest speaker, delivering a thought-provoking and practice-challenging presentation on his work on dignity conserving care at the end of life.

Constituency groups

Throughout the year the Partnership's network of constituency groups continued to meet regularly, providing

opportunities to stay up to date with current developments, consult on proposed new strategies and initiatives, and share good practice. The National Clinical Lead for Palliative Care attended and provided updates on progress towards and implementation of *Living and Dying Well*, and a representative from Audit Scotland updated the Specialist Palliative Care Group on its study of palliative care services in Scotland. A number of groups enjoyed detailed presentations on amended Scottish Government guidance regarding NHS continuing healthcare and the Scottish Ambulance Service End of Life Care Plan, and all groups were able to discuss proposed Scottish Parliament Bills and the Partnership's proposed constitutional amendments.

Facilitating a national conversation on care, loss, death and dying

The Scottish Partnership for Palliative Care was closely involved in producing *Living and Dying Well*, and is represented on all of the short-life working groups set up to carry out further development work in specific areas. In addition, the Partnership has been asked to take the lead in one of these areas, and has set up a working group to develop recommendations on addressing palliative and end of life care from a public health and health promotion perspective. The group comprises representatives from a range of backgrounds and will report by March 2010. It sees its task in terms of identifying ways of facilitating a national conversation on care, loss, death and dying and addressing society's current lack of knowledge and familiarity with these issues.

Lymphoedema

The Partnership's persistence in keeping the issue of appropriate services for people with primary lymphoedema firmly on the political agenda, in particular by bringing it twice to the agenda of the Cross Party Group in the Scottish Parliament on Palliative Care in recent years, was rewarded in May 2008 when the Cabinet Secretary for Health and Wellbeing, launching the findings of a lymphoedema service mapping project at the University of Glasgow, announced that primary lymphoedema would henceforth be recognised as a long-term condition in its own right. This addresses the unequal access to lymphoedema services funded under cancer budgets experienced by those whose condition had not arisen as a result of cancer or cancer treatments and ensures the inclusion of primary lymphoedema within the long-term conditions strategy. A further positive development announced by the Cabinet Secretary was the decision by NHS Quality Improvement Scotland to develop for re-issue in Scotland the British Lymphology Society's International Consensus Document *Best practice for the management of lymphoedema*.

Palliative care in care homes

In March 2009 the Care Commission published its palliative care report *Better Care Every Step of the Way*, revealing the short-comings in end of life care in care homes in Scotland and reflecting the findings of 1036 inspections and three

investigations carried out by the Care Commission in care homes for older people between April 2007 and March 2008. These were the first inspections based on *Making good care better National practice statements for general palliative care in adult care homes in Scotland*, published jointly by the Care Commission and the Scottish Partnership for Palliative Care in May 2006, and the 2009 report represents a significant step forward in raising standards of care for this vulnerable group.

Scottish Ambulance Service End of Life Care Plan

Further collaboration was evidenced by the joint publication in May 2008 by the Scottish Ambulance Service (SAS) and the Scottish Partnership for Palliative Care of an *End of Life Care Plan*. Developed jointly by SAS and members of the Partnership's Specialist Palliative Care Group, the plan provides guidance for all SAS staff involved in caring and arranging transport for palliative care patients and in training staff in their needs.

Scottish Parliament

The Partnership continued to provide the secretariat for the *Cross Party Group in the Scottish Parliament on Palliative Care* and to ensure a series of meetings of interest and relevance to members. The recent report *Living and dying with advanced heart failure: a palliative care approach*, published jointly by the Scottish Partnership for Palliative Care and British Heart Foundation Scotland, was presented in June 2008, while a joint meeting with the Cross Party Group in the Scottish Parliament on International Development, highlighting palliative care needs in developing countries, was held in October 2008. This will be followed up by interested MSPs as well as by palliative care professionals. Meetings in January and February 2009 provided a forum for MSPs Margo MacDonald and Roseanna Cunningham to present proposals for their End of Life Choices (Scotland) Bill and Palliative Care (Scotland) Bill respectively, and for members of the group to discuss these and to express their views. Following a consultation process, the Convener was able to submit a formal response from the Cross Party Group to both proposed Bill consultations.

Financial review

The Partnership recorded a net surplus for the year of £18,803. Unrestricted income of £257,218 was generated mainly from

In December 2008, Pat Wallace intimated to Council her longstanding intention to retire on reaching the age of 60 in December 2009. It seems right and proper, and indeed I am honoured, to begin my review of the successes, achievements and significant impact of the Partnership with some reflections about Pat. After Council realised that persuasion would have no impact on her decision, the size of the task became apparent - to ensure the Partnership continues to maintain its position as the effective force for change in palliative care in Scotland.



Maria McGill, Chairman

During her seven years as Director of the Partnership, Pat's visionary leadership has ensured that palliative care is now firmly top of the political agenda. In addition her ability to form effective strategic partnerships with other national organisations has resulted in seminal reports effecting real and lasting change in palliative care services, in particular for people in care homes and for people with advanced heart failure. Between 2002 and 2006, Pat developed and led our innovative Big Lottery funded project *Joined Up Thinking, Joined Up Care*, designed to improve access to palliative care services for those with life-threatening conditions other than cancer. This provided the strategic platform which created the environment in which the challenges in providing palliative and end of life care for all, based on need not clinical diagnosis, could be met. Pat's unique ability and tireless influence in bringing the right partners to the discussions has led directly to the subsequent developments in provision of palliative care and end of life care services across all sectors in Scotland.

The key achievement for both Pat and the Partnership in 2009 is clearly the publication and launch of *Living and Dying Well* and the subsequent widespread support for its implementation. The palliative care community has fully embraced the philosophy of the report and is actively engaged with health and social care colleagues to ensure that this report doesn't simply sit on a shelf gathering dust. With this action plan we have a genuine opportunity to facilitate the transformation of palliative and end of life care for patients, carers and their families across Scotland, regardless of care setting and regardless of diagnosis.

With the evidence of *Living and Dying Well* and with Council's two-year review of corporate and strategic governance now almost complete, I believe the Partnership has once again demonstrated itself to be a robust organisation both willing and able to respond to the rapidly changing context in which we all operate. This review makes sure the Partnership is 'fit for purpose' as we prepare for our future.

And we can be sure that the future will be extremely demanding for the Partnership on several fronts as we anticipate the outcome of the work associated with *Living and Dying Well*, in particular the prospect of facilitating a national conversation on care, loss, death and dying. In addition, the forthcoming progress through the Scottish Parliament of Margo Macdonald's draft End of Life Choices (Scotland) Bill and the Proposed Palliative Care (Scotland) Bill launched by Roseanna Cunningham MSP and to be taken forward by Gil Paterson MSP will no doubt present both opportunities and challenges. In this exciting climate I am confident that the Partnership will continue to have a significant impact on the development of palliative care services, exceeding even our own high hopes and dreams.

Finally I offer my congratulations and sincere thanks to the hard-working, small and perfectly formed staff team of the Partnership and to my Council colleagues for their ongoing commitment to the vision of palliative care for all based on need, not diagnosis.

Scottish Partnership for Palliative Care

Member Organisations at 31 March 2009

NHS Boards

NHS Ayrshire and Arran
NHS Borders
NHS Dumfries and 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 Scotland
British Lung Foundation Scotland
Cancer Support Scotland (Tak Tent)
Chest, Heart and Stroke, Scotland
CLIC Sargent
Macmillan Cancer Support
Maggie's Cancer Caring Centres
Marie Curie Cancer Care
MND Scotland
Multiple Sclerosis Society Scotland
Parkinson's Disease Society
Roy Castle Lung Cancer Foundation
Scottish Conference of Cancer Support Groups
Scottish Huntington's Association
Scottish Kidney Federation
Sue Ryder Care
The Stroke Association

Professional Associations

Association for Palliative Medicine
Association of Bereavement Service Co-ordinators
Association of Hospice and Palliative Care Chaplains
Association of Palliative Care Social Workers
RCN Palliative Nursing Group
Scottish Palliative Care Pharmacists Association

Support Organisations

Cancer Link Aberdeen and North (CLAN)

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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. Council also records its thanks to the British Heart Foundation Scotland for restricted funds of £593 received during the year. Employment costs formed the most significant element of the £239,008 unrestricted expenditure. There were underspends on salaries due to maternity leave arrangements and on publications due to work on the Scottish Government Action Plan for palliative and end of life care, *Living and Dying Well*.

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, the Care Commission, NHS Education for Scotland, NHS Quality Improvement Scotland, the Scottish Ambulance Service, Marie Curie Cancer Care, Macmillan Cancer Support, Help the Hospices and the National Council for Palliative Care. We would like to extend our gratitude and appreciation to all those individuals and organisations who continue to support and work with us, contributing to constituency groups and working groups, responding to consultations, providing information and advice and giving generously and consistently of their time, effort, expertise and commitment. The success of this organisation, and the achievements of the past year, are due to you. Thank you.

Scottish Partnership for Palliative Care

Core income and expenditure account for the year ended 31 March 2009

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 2009)

Maria McGill Chairman	Chief Executive, Highland Hospice
Kate Lennon Deputy Chairman	Macmillan Nurse Consultant in Palliative Care, NHS Greater Glasgow & Clyde
Tom Gault Honorary Treasurer	Chief Executive, St Andrew's Hospice
Maureen Black	Senior Macmillan Development Officer, Macmillan Cancer Support
Dr David Carroll	Associate Specialist in Palliative Care / GP Facilitator, NHS Grampian
Vicky Freeman	Cancer Services Programme Manager, NHS Dumfries and Galloway
Linda Kerr	Nurse Specialist in Palliative Care, NHS Ayrshire and Arran
Trudy Lafferty	Matron, St Vincent's Hospice
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
Margaret White	Associate Director Hospices UK, Marie Curie Cancer Care
Anne Willis	Hospice Manager, Marie Curie Hospice, Edinburgh

Observers

Mark Aggleton	Scottish Government Health Directorates
Dr Jennifer Armstrong	Scottish Government Health Directorates
Colin Brown	Scottish Government Health Directorates
Richard Dimelow	Scottish Government Health Directorates
Eve Richardson	National Council for Palliative Care

Staff

Pauline Britton	Publications & Group Liaison Officer
Eric Chen	Policy Assistant (Maternity cover)
Susan Diotaiuti	Executive Assistant / PA to the Director
Claire Femister	Finance & Administration Manager
Rebecca Patterson	Policy Manager
Patricia Wallace	Director

	31.03.08	31.03.09
	£	£
Income		
Grants for core administration costs:		
- Scottish Government Health Directorates	87,000	112,000
- Macmillan Cancer Support	20,600	20,600
- Marie Curie Cancer Care	20,500	21,000
Member subscriptions	69,196	71,709
Interest on deposit	5,315	3,715
Annual conference	14,920	28,194
	217,531	257,218
Expenditure		
Salaries, NI and pensions	161,133	162,440
Rent	9,500	10,752
Water rates	687	706
Insurance	1,368	1,366
Light and heat	2,650	2,340
Maintenance and repairs	5,263	8,020
Cleaning	1,844	2,302
Stationery	4,012	4,475
Printing and publications	8,308	11,484
Postage	2,671	2,363
Telephone	1,512	1,372
Travel and meetings expenses	4,586	4,732
Annual conference	3,981	14,422
Audit fee	1,000	1,580
Professional fees	0	5,935
Recruitment	0	0
Training and development	0	845
Office equipment	0	0
General expenses	554	45
Depreciation of office equipment	1,779	3,439
Membership subscriptions	0	390
	210,848	239,008
Surplus / (deficit) for the year	6,683	18,803
Accumulated surplus brought forward	93,161	99,844
	99,844	118,647

Restricted funds income and expenditure account for the year ended 31 March 2009

	2008	2009
	£	£
Marie Curie Cancer Care <i>(reprint of Making Good Care Better)</i>		
Grant received during the year	3,390	0
Expenditure during the year	(3,390)	0
British Heart Foundation Scotland <i>(publication of Living and Dying with advanced heart failure)</i>		
Grant received during the year	3,000	593
Expenditure during the year	(3,000)	(593)

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.