# Scottish Partnership for Palliative Care

# **Annual Review**

for the year ended 31 March 2010



# Directors' Report for the year ended 31 March 2010

# Aims of the Partnership

A strategic and governance review of the Scottish Partnership for Palliative Care in 2007-2008 identified the following aims for the organisation:

- 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 three-year outline work plan for 2008-2011 and in detailed work plans for 2008-2009, 2009-10 and 2010-11 approved by the Council of the Partnership.

# How the Partnership works

The Partnership provides a unique mechanism through which organisations and practitioners involved in palliative care can engage with each other whether they are in primary, secondary, voluntary, statutory, health or social care settings and on a multi-disciplinary basis. It is this whole system perspective which underpins the Partnership's policy development and problem solving work and informs its advice to the Scottish Government, with whom it works closely. In practical terms the Partnership runs a regular network of meetings which brings together interested parties on both a geographical and interest group basis. It also runs short life working groups to address specific topics and is able to harness readily a wide range of clinical and non-clinical expertise. Through its website, information bulletins, annual conference and publications the Partnership promotes and disseminates the latest good practice. The Partnership also monitors relevant Parliamentary activity and provides the secretariat to the Cross Party Group on Palliative Care.

### **Achievements**

# Living and Dying Well

During 2009-2010 the Partnership continued to play a key role in supporting the implementation of Living and Dying Well, a national action plan for palliative and end of life care in Scotland. The Partnership was represented on all the working groups established to carry out further development work in specific areas.

#### Health Promoting Palliative Care

The Partnership led a working group (under the auspices of Living and Dying Well) which explored and then reported to the Scottish Government on 'Addressing palliative and end of life care from a public health and health promotion perspective: facilitating wider discussion of death, dying and bereavement across society'. A draft of the report was widely consulted upon and was well received. The report, received by the Scottish Government, called for the establishment of an Alliance to lead and co-ordinate further work in this area. This Alliance should be tasked specifically with raising public awareness and promoting community involvement in the issues of death, dying and bereavement across central and local government and appropriate agencies and organisations in all

sectors of Scotland's multi-cultural and multi-faith society.

# **Quality Standards**

During the year the Partnership contributed to the development of NHS Quality Improvement Scotland (QIS) clinical standards in Chronic Obstructive Pulmonary Disease (COPD), Heart Disease and Neurological Health Services. The Partnership carried out work which will eventually result in the publication of a guide to research in palliative care, which will support the development of a stronger evidence base in palliative care.

#### Annual Conference

Entitled 'Palliative Care: how can we make a difference?' the Partnership's annual conference was attended by 244 people from different professional and organisational backgrounds. A diverse programme included presentations on the Liverpool Care Pathway, therapeutic encounters, palliative care in acute hospitals, palliative care for children and younger people, people with learning disabilities, people with non-malignant disease and a perspective from England on future challenges for end of life care.

### Constituency Groups

Through the year the Partnership's network of constituency groups continued to meet. These meetings



Mark Hazelwood, Director

supported better cross sector and inter-professional communications, knowledge and intelligence which are critically important for continuous improvement. The groups enabled members to keep up to date on new initiatives, share best practice and input to policy development. Specific topics included; national Do Not Attempt Cardiopulmonary Resuscitation (DNACPR) policy; End of Life Assistance (Scotland) Bill; all work streams associated with *Living and Dying Well;* implementation of the electronic Palliative Care Summary (ePCS); palliative care in heart failure and the handling of controlled drugs.

#### Scottish Parliament

The Partnership continued to keep its membership informed about relevant developments and provided factual briefings on the content and progress of the Palliative Care (Scotland) Bill and the End of Life Assistance (Scotland) Bill. The Partnership provided the secretariat for the Cross Party Group in the Scottish Parliament on Palliative Care. Meetings of the Group considered topics including international perspectives on palliative care, General Medical Council (GMC) guidance on end of life decision-making and physician assisted suicide and euthanasia.

## Internal Changes

In order to ensure it remained fit for purpose the Partnership completed a governance review and amended its constitution at the AGM in September.

A redesign of the Partnership's website was conducted. The Partnership's longstanding and successful Director Pat Wallace retired and was replaced by Mark Hazelwood.

#### Future plans

Despite the higher profile of palliative care and the steps taken to implement *Living and Dying Well* there remains much to be done before the objects of the Partnership are realised. High quality care is not currently accessible to all who need it.

In this context, during 2010–2011 the Partnership plans to:

- I. Identify and capitalise on opportunities in priority areas emerging from Living and Dying Well (eg care homes, acute settings, dementia, children / adolescents / young people)
- 2. Input to and influence NHS QIS's palliative care programme
- 3. Take forward at least one piece of work relating to public health approaches to palliative care
- 4. Input directly and support members to input to the parliamentary processes connected with the

- End of Life Assistance (Scotland) Bill and consider the next steps in relation to the final outcome of the End of Life Assistance (Scotland) Bill
- 5. Maintain the smooth operation of our constituency group infrastructure
- 6. Run a successful conference
- 7. Further develop our website
- 8. Complete and publish our Guide to Palliative Care Research
- 9. Engage in work to help develop a clear framework for health board funding of hospices and related specialist palliative care services
- 10. Seek to add to our sources of income
- 11. Review and develop our strategy so that we continue to maximise our impact.

## **Key Partners**

The Partnership's effectiveness as an organisation and its success in delivering its objectives depends to a large extent on the commitment and participation of its members and other partners. Our relationship with members is vitally important as are our links with other national bodies such as the Scottish Government Health Directorates, the Care Commission, NHS QIS, NHS Education for Scotland (NES), Marie Curie Cancer Care, Macmillan Cancer Support, the Scottish Ambulance Service, Help the Hospices and the National Council for Palliative Care.

Once again we would like to thank all those organisations and individuals who make the work of the Partnership possible in so many different ways; by contributing to working groups; responding to consultations; providing information and advice; and sharing their time, effort and expertise. Without your commitment the achievements detailed in this report would not have been possible.

# Structure, Governance and Management

The Partnership 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 together form its constitution. The Memorandum and Articles were adopted on 7 May 1991 and were last amended on 30 September 2009.

The Scottish Partnership for Palliative Care is a membership organisation. At 31 March 2010 there were 53 member organisations, comprising NHS Boards, voluntary hospices, national charities and support organisations and professional associations.

Each member organisation nominates a representative or representatives 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.

As required by the Articles of Association, the membership of the Partnership is divided into regional and national constituency groups as follows:

- National Charities Group
- North Regional Group
- Scottish Hospices Forum
- South East Regional Group
- Specialist Palliative Care Group
- West Regional Group.

Each constituency group elects two representatives (except the West Regional Group which elects four) to act as Council Members for the Partnership.

The governing body of the Partnership is the Council whose members are elected from the organisation's constituent groups. Council Members serve as Company Directors of the Scottish Partnership for Palliative Care, and function as the charity trustees. The Council is responsible for the governance and management of the charity. A full time Director is appointed to manage the day to day operation of the Partnership.

#### Financial Review

The Partnership recorded a net deficit for the year of £972 (2009: a surplus of £18,803).

Unrestricted income of £254,060 (2009: £257,218) 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 costs.

Employment costs formed the most significant element of the £255,032 (2009: £239,008) unrestricted expenditure.

# Chairman's Report

This is the fourth occasion on which I have had the privilege of reporting as Chairman of the Partnership to the membership and other stakeholders. Each year has seen important achievements by the Partnership and significant change in the environment in which we operate. What has not changed is the absolute commitment of all involved in the Partnership to achieving equitable access to palliative care.



Maria McGill, Chairman

The year to March 2010 was dominated by the huge amount of exciting work associated with implementation of *Living and Dying Well*, the Scottish Government's action plan on palliative and end of life care. This plan has presented the palliative care community in Scotland with a number of unique opportunities to progress long-cherished aims and developments. The energy and commitment with which those opportunities have been grasped has been fantastic. I have also been thrilled to see, as palliative care has achieved a higher profile and priority, the way in which its development has been championed and supported by individuals and organisations which have only recently had opportunity to become engaged in this area of work.

2009 saw internal change at the Partnership. Changes to the constitution were finally implemented. Our longstanding and visionary Director, Pat Wallace retired in December and we were pleased to welcome Mark Hazelwood into post as her successor.

2011 will see the 20th Anniversary of the establishment of the Partnership. Whilst it is important to understand and value the Partnership's history it is also important to look ahead to the new challenges which we know will face us as we continue to strive to achieve equitable access to palliative care in Scotland. Whilst equitable access to palliative care is now well established and accepted policy at national and local level, there remains much to be done before this becomes a consistent reality for the people of Scotland. At the same time all organisations involved in palliative care face increasingly difficult financial circumstances. We also know that demographic change will increase the demand for services. We face also the possibility of legislation which would require adaption in the practice of palliative care. We know there is work to do to understand the best way to provide care for people with different conditions and then to design services which can deliver that care. There are also huge opportunities to encourage and support more open and informed public discussion about end of life issues. The Partnership will need to bring to these challenges the same energy, commitment and positive attitude which have been the key to its past successes.

In conclusion I would like to thank the small but dedicated staff of the Partnership for their efforts over the past year, without whom the work of the Partnership would have ground rapidly to a halt. I also wish to record my gratitude to my colleagues on the Council for their thought and input to the oversight of the Partnership and for their personal support to me as Chairman.

# Scottish Partnership for Palliative Care Member Organisations at 31 March 2010

# **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 and 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 and NI

Cancer Support Scotland (Tak Tent)

**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 Care Nursing** 

Scottish Palliative Care Pharmacists Assocation

# **Support Organisations**

Cancer Link Aberdeen and North (CLAN)

# Scottish Partnership for Palliative Care

Core income and expenditure account for the year ended 31 March 2010

Honorary Presiden	nt		31.03.09	31.03.10
Dr Derek Doyle OBE MB C	hB FRCS FRCP FRCGP		£	£
		Income		
Honorary Vice President		Grants for core administration costs:	112 000	112 000
Professor Sir Kenneth Calman KCB MD FRCS FRSE		<ul><li>Scottish Government Health Directorates</li><li>Macmillan Cancer Support</li><li>Marie Curie Cancer Care</li></ul>	112,000 20,600 21,000	112,000 21,300 21,000
Council (as at 31	March 2010)	Donations	0	205
Maria McGill	Chief Executive.	Members subscriptions	71,709	74,126
Chairman	Highland Hospice	Interest on deposit	3,715	229
<u> </u>	The final decrease of the first state of the first	Annual conference	28,194	25,200
Kate Lennon	Macmillan Nurse Consultant in Palliative Care,			
Deputy Chairman	NHS Greater Glasgow and Clyde		257,218	254,060
Tom Gault	Chief Executive,	Expenditure		
Honorary Treasurer	St Andrew's Hospice	Salaries, NI and pensions	162,440	192,542
		Rent	10,752	11,508
Dorothy McElroy	Chief Executive,	Water rates	706	566
Acting Honorary Treasurer	Ardgowan Hospice	Insurance	1,366	1,362
D D :16 "	A	Light and heat	2,340	2,126
Dr David Carroll	Associate Specialist in Palliative Care /	Maintenance and repairs	8,020	2,632
	GP Facilitator, NHS Grampian	Cleaning	2,302	2,744
Landa Balla	11 1 66 11 1	Stationery	4,475	3,032
Lorraine Dallas	Head of Scotland,	Printing and publications	11,484	3,823
	Breast Cancer Care, Scotland	Postage	2,363	3,035
V:-I F	Grand State December Management	Telephone	1,372	1,977
Vicky Freeman	Cancer Services Programme Manager,	Travel and meetings expenses	4,732	7,677
	NHS Dumfries and Galloway	Annual conference	14,422	7,791
Linda Kerr	NI C taltus to Dallitust o Co	Audit and taxation fees	1,580	2,055
Linda Kerr	Nurse Specialist in Palliative Care,	Legal and professional fees	5,935	2,218
	NHS Ayrshire and Arran	Recruitment	0	5,568
Touche Leffonts	Matura	Advertising	0	500
Trudy Lafferty	Matron,	Training and development	845	80
	StVincent's Hospice	General expenses	45	19
Dr David Oxenham	Consultant in Palliative Medicine.	Depreciation of office equipment	3,439	3,439
Dr David Oxemani	NHS Lothian	Membership subscriptions	390	338
Dr Chris Sugden	Consultant in Palliative Medicine,		239,008	255,032
-	St Andrew's Hospice			
	•	Surplus / (deficit) for the year	18,803	(972)
Margaret White	Assistant Director Hospices,	Accumulated surplus brought forward	99.844	118,647
-	Marie Curie Cancer Care	. tees. indiaced sail plas of ought for ward		
			118,647	117,675
Anne Willis	Hospice Manager,			
	Marie Curie Hospice, Edinburgh			

#### **Observers**

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

Susan Diotaiuti Executive Assistant / PA to the Director

Claire Femister Finance & Administration Manager

Mark Hazelwood Director
Rebecca Patterson Policy Manager

# Restricted funds income and expenditure account for the year ended 31 March 2010

	2009	2010	
	£	£	
British Heart Foundation Scotland (publication of Living and Dying with advanced heart failure) Grant received during the year Expenditure during the year	593 (593)	0	

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.