

# Scottish Partnership for Palliative Care

## *Annual Review*

*for the year ended 31 March 2011*

## Director's Report

This review covers a period which coincided with my first full year working with the Partnership. I have been inspired by the energy, enthusiasm and whole heartedness with which those in this field convert their passion into practical action. There is no shortage of challenges facing palliative care. I have structured my report on the year around some of these major issues which the Partnership is addressing.

### *The Demographic Challenge*

Scotland has an ageing population, with the number of people with dementia expected to double to 140,000 over the next twenty years, and rising numbers of people dying at an older age following an extended period of ill health.

In October the Partnership worked with Scottish Care, NHS Education Scotland and the Care Commission to run a conference on palliative care for care home providers. The event was attended by over 250 people and was positively evaluated.

In March the Partnership worked with Napier University and Alzheimer's Scotland to run a summit entitled '*Living and Dying Well with Dementia*'. This event brought together participants with a strategic or academic role in health, social care or government to share challenges, find solutions and showcase examples of best practice on meeting the needs of people with dementia and their families. The Partnership also provided input to an end of life care standard for dementia being developed by the Mental Welfare Commission.

Towards the end of the year the Partnership worked with Marie Curie Cancer Care to promote the role of palliative and end of life care within the Scottish Government's programme '*Reshaping Care for Older People*'.

### *The Challenge of Informing Decision Makers*

The year saw an unprecedented level of activity concerning palliative care and related issues in the Scottish Parliament. Following formal consultation with its membership the Partnership submitted written evidence to the committee scrutinising the End of Life Assistance (Scotland) Bill. The Partnership's aim was to support the deliberation of MSPs both by providing relevant factual information and also by directing the attention of MSPs to questions of practical relevance to two particular considerations: firstly, any possible damage to the practice and provision of palliative care which might be caused by the Bill and secondly, the protection of vulnerable people. The Partnership also provided oral evidence to the committee. The Partnership's evidence was quoted by the Cabinet Secretary for Health during the final debate on the Bill in the chamber. The Partnership also provided written and oral evidence to the Scottish Parliament on the Palliative Care (Scotland) Bill. During the year the Cross Party Group on Palliative Care met on three occasions, with the Partnership continuing to provide the secretariat for the group. Topics covered were assisted suicide, euthanasia and the End of Life Assistance (Scotland) Bill, the Dementia Strategy and the Palliative Care (Scotland) Bill.

Despite the welcome level of parliamentary interest, most decisions in palliative care are not about determining the legal, moral and ethical frameworks in the way in which our legislators did during the year. Most decisions concern judgements about how to provide the best care for the individual patient and their



*Mark Hazelwood, Director*

family who need support now. When faced with these every day judgements practitioners and service planners need a strong evidence base. It was this belief, and an awareness that the evidence base in palliative care would benefit from strengthening, which led the Partnership to convene a group to produce a relevant publication. In February the Partnership published '*A Beginner's Guide to Successful Palliative Care Research*'. This resource aims to support and encourage, through practical advice and direction, practitioners who wish to undertake relevant research and hence contribute to the development of the palliative care evidence base.

### *The Challenge of Turning Policy into Reality*

It is a tribute to the work of the Partnership over many years that the provision of palliative care on an equitable basis in all settings is embedded in national and local policy across Scotland. The real challenge is now to turn that policy into a consistent reality: the outcome of that challenge is

experienced by tens of thousands of people in Scotland every year. During the year the Partnership developed its role in supporting the implementation of *Living and Dying Well* the government's national action plan on palliative and end of life care. The Partnership took on a secretariat and project management function for the National Advisory Group overseeing implementation of the action plan. In addition the Partnership made commitments to support specific aspects of implementation, more detail of which is provided in 'Future Plans' below.

### ***The Challenge of Making Palliative Care Everybody's Business***

The aspiration to provide palliative care for all who need it cannot be met without palliative care being recognised as a core activity in settings and by practitioners who have perhaps not traditionally seen palliative care as their business. This principle applies beyond the confines of health and social care and extends to a need to promote more openness about death, dying and bereavement in Scottish society more widely; death is normal and there are ways in which people can help each other to live with death, dying and bereavement. Building on the recommendations of its earlier report on health promoting palliative care the Partnership began preparatory work to establish an alliance of organisations and individuals to undertake such work. The alliance will aim to raise awareness of ways of living with death, dying and bereavement and will also aim to increase community involvement in such issues.

In 2010 the Partnership created the new category of 'Associate Member' which allowed care homes, local authorities, umbrella bodies and academic institutions to link formally to the Partnership for the first time. 23 Associate Members took advantage of this opportunity during the year.

During the year the Partnership assembled a small group to work with the Scottish Ambulance Service to update guidance on end of life care.

### ***The Challenges of Efficiency and Effectiveness in a Time of Austerity***

Throughout the year the Partnership continued to pursue its core business of problem solving and good practice. In a time of austerity it is particularly important to be able to share problems and solutions and to avoid reinventing the wheel in local isolation. To this end, and to supplement our traditional constituency group networks, the Partnership launched a monthly e-bulletin UPDATE which provides a regular selection of news, events, research, policy and practice of relevance to those involved in palliative care in Scotland. UPDATE reaches around 3000 people each month.

The Partnership's annual conference in October brought together nearly 250 people from health, social care, academic and housing sectors to engage in a range of topics from health promoting palliative care to compassionate care.

### ***Future plans***

The challenges cited above are likely to set the agenda for the Partnership for the next few years at least. The Partnership has agreed five strategic objectives for the next three years (April 2011 – March 2014):

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

The main new areas of work for the Partnership between March 2011 and April 2012 include:

- providing reporting, intelligence-gathering and secretariat support to the National Advisory Group for *Living and Dying Well*
- developing and supporting a mechanism for the ongoing review and update of national clinical palliative care guidelines
- maintaining, reviewing and updating patient/carer information on palliative care on the NHS Inform website
- launching an Alliance to promote more openness about death, dying and bereavement in Scottish society
- working to strengthen patient and carer voices in palliative care policy making.

## Chairman's Report

The Scottish Partnership for Palliative Care was established in 1990 to establish and maintain links among all bodies involved with the provision of palliative care in Scotland. A network rather than a structure was envisaged. In the Partnership founding document Tom Scott, the founding author, described the need for a flexible agency able to respond to the emerging and changing scene in palliative care. Since then, it is clear that the work of the Partnership, as it has become affectionately known, has both respected and cherished Tom's aspiration and indeed his legacy. The current financial climate has impacted significantly on public spending. This difficult environment creates opportunities for new thinking and creative solutions to challenges and the Partnership is well placed to further develop innovative approaches in its work. We are now actively embracing the digital revolution and the much loved quarterly *Update* has become a monthly e-news bulletin with a fresh and current look. The purchase of video-conferencing equipment for the office will enable cost effective and regular communications with external organisations ensuring immediacy and continued relevancy of our work and immediate contact in the dynamic shifting national environment.



Maria McGill, Chairman

Our considered parliamentary involvement in matters relating to palliative care has ensured that MSPs are aware of the extent of the issues and that they are provided with relevant factual information to further inform their decision making. Undoubtedly these issues will, and should, continue to invite comment and discussions not only in Parliament but in our wider society.

When *Living and Dying Well* was being developed I am sure that the Partnership did not consider that it would be involved so intimately in its continuing implementation. The involvement in the National Advisory Group and support from NHS Boards and other colleagues in the implementation of *Living and Dying Well: Building on Progress* ensure the Partnership continues to be at the heart of palliative care in Scotland.

The Partnership was delighted to be invited by the Scottish Government to lead the development of a national alliance to raise public awareness and promote community involvement in issues relating to death, dying and bereavement. This is a clear indication of the respect for the work and the impact of the activities of the Partnership, and once again the creative approaches of the organisation will be utilised as it seeks to influence and change attitudes and behaviours towards death, dying and bereavement. We continue to ask the fundamental questions, '*Have you talked about your wishes towards the end of your life, including where you want to die and your funeral plans with friends, family and loved ones? If not, why not?*'

Since 2006 I have been honoured to serve the Partnership in a variety of roles. This, my final annual report, has provided as ever a structured space within which to reflect on the successes, achievements and changes in the year to date – as well as offering a view of the future. The Partnership has remained at the heart of significant change, continues to be responsive to the emerging needs and changes in our society today and also leading the changes beyond the world of palliative care, not least by promoting public discussion of issues relating to death, dying and bereavement.

The Partnership achieves this increasingly by using creative and sophisticated approaches to communicate with the wider community of Scotland. I believe that this and its many achievements this last year makes it a national organisation of which Scotland can be rightly proud.

I would like to take this opportunity to pay tribute to and thank my Council colleagues, the staff team for their unstinting energy, commitment and support during my seven years of service with the Partnership. It has been both a pleasure and a privilege – thank you!



# Scottish Partnership for Palliative Care

## Member Organisations at 31 March 2011

### 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 and Northern Ireland  
British Heart Foundation Scotland  
British Lung Foundation Scotland and Northern Ireland  
Cancer Support Scotland 'Tak Tent'  
CLIC Sargent  
Macmillan Cancer Support  
Maggie's Cancer Caring Centres  
Marie Curie Cancer Care  
MND Scotland  
MS Society Scotland  
Parkinson's UK  
Scottish Conference of Cancer Support Groups  
Scottish Huntington's Association  
Scottish Kidney Federation  
Sue Ryder Care  
The Progressive Supra Nuclear Palsy Association  
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  
Independent Association of Nurses in Palliative Care  
RCN Palliative Nursing Group  
Scottish Palliative Care Pharmacists Association

### Support Organisations

CLAN Cancer Support

# Scottish Partnership for Palliative Care

Core income and expenditure account  
for the year ended 31 March 2011

## 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 2011)

Kate Lennon Chairman	Macmillan Nurse Consultant in Palliative Care, NHS Greater Glasgow and Clyde
Deputy Chairman	Vacancy
Derek Blues Honorary Treasurer	Managed Care Network Manager, NHS Forth Valley
Rhona Baillie	Chief Executive, Prince & Princess of Wales Hospice
Elaine Burt	Head of Nursing, Rehabilitation and Assessment Directorate, NHS Greater Glasgow and Clyde
Dr David Carroll	Associate Specialist in Palliative Medicine/ GP Facilitator, NHS Grampian
Lorraine Dallas	Head of Scotland, Breast Cancer Care, Scotland
Linda Kerr	Nurse Specialist in Palliative Care, NHS Ayrshire and Arran
Dr Peter Kiehlmann	General Practitioner, NHS Grampian
Dorothy McElroy	Chief Executive, Ardgowan Hospice
Dr Gordon McLaren	Consultant in Public Health Medicine, NHS Fife
Dr David Oxenham	Consultant in Palliative Medicine, NHS Lothian
Dr Euan Paterson	General Practitioner, NHS Greater Glasgow and Clyde
Elaine Stevens	Lecturer in Cancer and Palliative Care, Independent Association of Nurses in Palliative Care
Margaret White	Assistant Director Hospices, Marie Curie Cancer Care
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

	31.03.10	31.03.11
	£	£
<b>Income</b>		
Grants for core administration costs:		
- Scottish Government Health Directorate	112,000	148,500
- Macmillan Cancer Support	21,300	20,000
- Marie Curie Cancer Care	21,000	21,000
Donations	205	-
Members subscriptions	74,126	76,024
Interest on deposit	229	307
Annual conference	25,200	25,000
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	254,060	290,831
<b>Expenditure</b>		
Salaries, NI and pensions	192,542	175,078
Rent	11,508	11,458
Water rates	566	587
Insurance	1,362	1,836
Light and heat	2,126	1,688
Maintenance and repairs	2,632	3,831
Cleaning	2,744	3,293
Stationery	3,032	3,252
Printing and publications	3,823	9,419
Postage	3,035	3,251
Telephone	1,977	2,076
Travel and meetings expenses	7,677	3,401
Annual conference	7,791	19,552
Audit and taxation fees	2,055	1,868
Legal and professional fees	2,218	15
Recruitment	5,568	-
Advertising	500	-
Training and development	80	973
General expenses	19	-
Depreciation of office equipment	3,439	1,717
Membership subscriptions	338	415
Website	-	684
Bank charges	-	30
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	255,032	244,424
Surplus / (deficit) for the year	(972)	46,407
Accumulated surplus brought forward	118,647	117,675
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	117,675	164,082

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.