

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 2006

Chairman's Report

Reflections of a Decade in Palliative Care



Professor Frank Clark CBE, Chairman

In my final report as Chairman of the Partnership and at the end of a wonderful 10 year association with the world of palliative care I thought that it might be appropriate to reflect on how things have changed during the last decade.

It is clear that palliative care in all its forms has developed enormously in that time but it is in the last 5 years that I have observed and been involved in what can only be described as its exponential growth. It has been good to see the Partnership at the centre of that agenda with all of the attendant benefits for patients and their families.

Just over four years ago I presented a set of challenges to the Annual General Meeting of the Cross Party Group in the Scottish Parliament on Palliative Care and I have been heartened by the progress since then in 'most' areas.

The main challenge as I saw it then was to extend the benefits of palliative care to those with non-malignant conditions and I can think of nowhere in Scotland where this does not feature significantly on the health and social care agenda encouraged of course by the excellent Kerr Report and the White Paper 'Delivering for Health'. The Director's report refers to the Big Lottery Fund Project 'Increasing access to palliative care for people with life-threatening conditions other than cancer' and this outstanding piece of work will be launched at our Annual Conference in November by Lewis MacDonald, Deputy

Minister for Health and Community Care and Dr Harry Burns our Chief Medical Officer. The report will set new challenges for planners and providers alike and has been informed by substantial input from service users.

I also highlighted the increased range of settings in which palliative care would be delivered including the acute sector, intermediate care, community hospitals, care homes and increasingly in patients' own homes and other community settings. The launch of 'Making good care better – national practice statements for general palliative care in adult care homes in Scotland' marks another major step in driving up the standards of general palliative care throughout the care home sector and is another excellent example of partnership working between the Scottish Partnership for Palliative Care, the Care Commission and the Scottish Executive Health Department.

The need for and the benefits of quality assured palliative care education was another area in which I saw potential for development. Whilst the position at the level of higher education is good, work remains to be done in quality assuring the wide range of palliative care educational material in use throughout Scotland today. Consistency of quality and equity of access still need to be addressed. On the plus side, and with the support of NHS Education for Scotland (NES), we have undertaken a critical review of the multiplicity of palliative care competency frameworks which exist and the aim is to produce a report later in the year which will guide educationalists and service providers through this complex agenda.

The evidence base for palliative care remains underdeveloped (relative to a number of other clinical specialties) and we need to be less apologetic about qualitative research. Such research, provided that the methodology is soundly based and that the analysis and interpretation of findings is credible, will go a long way towards providing the evidence of what we know to be the case, that palliative care makes a beneficial difference. In Strathcarron Hospice where I work we have created a Medical Research Fellow and Research Nurse Practitioner who this year will complete an MD and a PhD respectively using qualitative research methodology. This output will add to the evidence base and will be of direct and practical benefit in developing standards in palliative care. The appointments of Professor Marie Fallon and Professor Scott Murray to palliative care chairs is particularly encouraging and I look forward to more exciting developments in palliative care research. I know that it is challenging and that time pressures can often be the enemy but I would like to see significantly more bids being made, for example, to the Chief Scientist Office for grants to enable further research to be undertaken in palliative care in Scotland.

Resourcing palliative care will of course always be an issue and extra finance in itself is not the answer. If we are to meet the challenge of developing high quality palliative care for all who need and can benefit from it and if we are to deliver care in the wider range of settings which I have mentioned above then we need to address the whole issue of more effective workforce planning in palliative care. We must engage in discussions on 'Modernising Medical Careers' to ensure that palliative medicine is presented as an attractive career option and we must address the challenge of where nurses and allied health professionals skilled in palliative care are going to come from in the future.

Effective inter agency working is essential to the delivery of palliative care and the advent of Community Health Partnerships provides a fresh opportunity to ensure that the benefits of palliative care are understood and appreciated and that palliative care is afforded priority when addressing the health care needs of local communities.

Much is said about raising public awareness of palliative care and I frequently hear ...

Continued on page 5

Director's Report

1 April 2005 to 31 March 2006



Patricia Wallace, Director

The Scottish Partnership for Palliative Care exists to 'promote, enhance, improve and extend the provision of palliative care services to patients suffering from life-threatening progressive conditions for the benefit of such people and their families throughout Scotland'. As the national umbrella and representative body for palliative care in Scotland, encompassing both statutory and voluntary sectors, it is able to offer to policy makers, planners, service managers and practitioners valuable opportunities for the development, sharing and implementation of expert opinion, sound strategy and good practice.

Core activities 2005-2006

Our activities in 2005-2006 reflected the developments, challenges and concerns of the wider health and social environment. We worked hard to respond appropriately, for example, to the implications of, on the one hand, a proposed Bill in the Scottish Parliament to legalise a form of assisted dying, and on the other, to the welcome challenges and opportunities presented in the Scottish Executive Health Department's report 'Delivering for Health' and the associated Kerr Report. We have been aware of an increasingly difficult financial climate for the NHS, local authorities and the voluntary sector, but also of potentially growing public awareness and demand for palliative care services arising from an unprecedented level of media focus on issues around death and dying. We have striven throughout the year to maintain a balance in our work between the growing focus on the palliative care needs of those with progressive non-malignant conditions and the continuing need for better and more equitable cancer services. In our aim to promote palliative care for all

who need it, regardless of care setting or of diagnosis, we have also attempted to reflect issues relating to both general and specialist palliative care, and have welcomed through some of our initiatives a growing involvement with primary care and with aspects of acute care to balance our existing structures and relationships.

The reference to 'palliative care for all' on some of our publications is a concise, and ambitious, expression of our aims. We hope that, thanks to the help of all who work with us, the achievements of the past year have represented a few of the necessary steps along the way.

Membership and Liaison

In addition to its member organisations, which include all NHS Boards in Scotland, all Scottish voluntary hospices and a range of national charities, support groups and professional associations for palliative care, the Partnership liaises closely with a number of national bodies in Scotland such as the Scottish Executive Health Department, NHS Quality Improvement Scotland, NHS Education for Scotland, the Scottish Commission for the Regulation of Care (Care Commission), the Scottish Ambulance Service, the Scottish Audit of Surgical Mortality and the Royal College of General Practitioners. We also work closely with NHS regional and local structures such as Managed Clinical Networks and Regional Cancer Networks. The Partnership is thus able to provide important communication and consultation links between all of these, facilitating the planning, provision and quality assurance of palliative care services at local, regional and national level.

We also continue to enjoy mutually productive relationships at UK level with bodies such as the National Council for Palliative Care, Help the Hospices, Macmillan Cancer Relief (now Macmillan Cancer Support) and Marie Curie Cancer Care.

Regional Constituency Groups

The Partnership's network of regional constituency groups, which mirrors the boundaries of regional cancer networks and includes NHS and voluntary representation, provides a comprehensive channel of communication for issues of national and regional import to and from NHS Boards and local palliative care Managed Clinical Networks and groups. It is

increasingly common, and productive, for members of one regional group to seek the views of their colleagues in other parts of the country through this mechanism. Each regional group works closely with existing regional cancer structures, and either forms or liaises with the appropriate regional forum for palliative care. Over the past year the **West Regional Group** continued to share information and to hold joint meetings with the West of Scotland Regional Managed Clinical Network for Palliative Care to consider issues of mutual concern. The MCN's focus on education and care of the dying as priorities in its workplan accords closely with aspects of the Partnership's national agenda. The completed West of Scotland Education Core Competency Framework was forwarded to the Partnership for inclusion in the work of its Competency Frameworks Advisory group (see page 4), while the MCN's recommendations in support of a wider adoption of the Liverpool Care Pathway were remitted to the Partnership Council and regional groups for discussion, and contributed to the setting up of the Partnership's short-life group on Palliative and End of Life Care (see page 4). Additional presentations and discussion topics at joint meetings included pain as a priority focus and the development of Community Health Partnerships and their potential impact on MCN working relationships. In **South East Scotland**, the Regional Group established a pattern of holding meetings consecutively with those of the SCAN Palliative Care Reference Group, formed this year after prolonged discussion and consultation within the South East Regional Group and SCAN to identify the most productive mechanism for ensuring a regional voice for palliative care. The regional group also heard presentations on the palliative care implications of the Kerr report, and on the Marie Curie 'Delivering Choice' project in Tayside and discussed a range of issues including lymphoedema and the transition of young people from paediatric to adult services.

The **North Regional Group** remained the single regional forum for palliative care in the north, working closely with NOSCAN and relevant NHS Boards and local palliative care groups. Its discussions ranged over end of life care, including the Liverpool Care Pathway and possible exit strategies for the Gold Standards Framework Scotland project, and issues involving ambulance transfers

and DNAR policies. Guest speakers included Professor Nora Kearney, who presented some of the findings of the Kerr Report, and Alison Poole, manager of the Partnership's Big Lottery Fund project (see below), who during the year updated all of the Partnership's constituency groups on the project's work and progress.

National Constituency Groups

The **Specialist Palliative Care Group** heard presentations on the Glasgow Heart Failure Liaison Service, palliative care and end-stage renal disease, the Gold Standards Framework Scotland project and the pan Lothian DNAR Policy. The group continued to advise and to receive reports from the Scottish Ambulance Service (SAS) regarding ambulance transfers and a patient pathway for palliative care, and supported the reported SAS intention to adopt the pan Lothian DNAR Policy across Scotland. They also continued to discuss and monitor closely the issues around disposal of controlled drugs following bereavement, and secured the inclusion of an appropriate statement regarding return of medicines to a community pharmacy in the new edition of the Scottish Executive publication 'What to do after a death in Scotland'. The attention of the **Scottish Hospices Forum** continued to focus largely on regulatory and quality assurance issues and mechanisms, with close liaison between the Forum and the Care Commission throughout the year as well as Forum representation on the NHSQIS Clinical Governance Risk Management Network. Negotiations between individual NHS Boards and hospices regarding the achievement of 50% funding of agreed running costs by April 2006 were also discussed, and largely positive progress reported. At UK and international level, links with Help the Hospices and a variety of initiatives including World Hospice and Palliative Care Day were maintained and developed. The **National Charities Group**, which welcomed the British Heart Foundation as a new member in 2005, continued to enjoy the sharing of information between its now balanced representation of cancer and non-cancer support organisations. A range of new developments was discussed, as well as the NHSQIS Chronic Pain Management Best Practice consultation and the future projected need for palliative care in care homes, particularly in relation to non-malignant conditions.

Council

As the governing body of the Scottish Partnership for Palliative Care, the Council is elected from the members of its constituency groups. Council receives reports from these groups, approves the organisation's workplan and financial arrangements, and in particular directs the future work of the Partnership through a range of initiatives and short-life working groups. A three-year workplan for 2005-2008 was approved and two new working groups were initiated during the year.

Working Groups

The **Competency Frameworks Advisory Group** was established with the support of NHS Education for Scotland to address the regulatory and quality issues raised by the existing multiplicity of palliative care competency frameworks. The group aims to provide guidance encouraging a consistent approach to these, linked to the current context of developments such as the NHS Knowledge and Skills Framework and the proposed NHS Scotland Careers Framework. Plans were also developed, with the support of the Scottish Executive Health Department and the Cross-Party Group in the Scottish Parliament on Palliative Care, for a new initiative in **Palliative and End of Life Care**, to be taken forward by a short-life working group in 2006. The **Care Homes Working Group** issued its draft national practice statements for palliative care in care homes for a three-month consultation period in the summer of 2005, and following analysis of responses will publish the final document in May 2006. Work on the report of the **Heart Failure Working Group** was unavoidably delayed, but should be completed in 2006-2007.

Big Lottery Fund Project



LOTTERY FUNDED

Our Big Lottery Fund Project 'Increasing access to palliative care for people with life-threatening conditions other than cancer' continued to progress on schedule with a comprehensive programme of consultation with patients and carers, health and social care practitioners, NHS Boards, local authorities and voluntary organisations. A study day programme based on educational needs identified by generic health and social care professionals was developed with the help of Marie Curie Cancer Care, education partners to the project, and will be piloted and evaluated in 2006.

Analysis of the consultation findings will be presented in the project's final report and recommendations, to be launched at the Partnership's annual conference 'Joined up thinking Joined up care ...' in Edinburgh on 22 November 2006.

Annual conference 2005

The annual conference at Dunblane on 14 September 2005 was attended by over 200 delegates. It focused, with the help of thought-provoking presentations by guest speakers Professor Julia Addington-Hall, Dr Marie Fallon and Professor Vivienne Nathanson and leaders of a wide range of workshop sessions, on present and future challenges for palliative care.

Scottish Parliament

The Partnership continued throughout 2005-2006 to raise awareness of palliative care issues in the Scottish Parliament, both by providing the secretariat for the Cross Party Group on Palliative Care in the Scottish Parliament and by providing information to the Scottish Executive Health Department in response to MSPs' questions. Discussions and presentations at Cross Party Group meetings this year dealt largely with issues around proposed legislation on assisted suicide and models of end of life care. Partnership Chairman Professor Frank Clark also met with the Minister for Health and Community Care in June 2005 to highlight the role of the organisation as well as key areas of our work and key priorities for palliative care development.

Publications and Information

We also continued to provide information and guidance on palliative care issues through publication of our Update newsletter and Courses and Conferences list, updating of our website, and by responding to a steady flow of queries via email, telephone and letter from individuals and organisations in Scotland, the UK and beyond.

Funding

None of this activity would be possible without the continuing support, financial and otherwise, of our member organisations and representatives and of our grant funders, the Scottish Executive Health Department, Macmillan Cancer Relief, Marie Curie Cancer Care and Help the Hospices. Thank you all for everything you have contributed over the past year towards our shared aim of ensuring that good palliative care is available on an equitable basis for all.

Scottish Partnership for Palliative Care

Member Organisations 1 April 2005 - 31 March 2006

NHS Boards

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

Voluntary Hospices

Accord Hospice
Ardgowan Hospice
Ayrshire 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

National Charities

Breast Cancer Care Scotland
British Heart Foundation
CancerBACUP Scotland
CLIC (Cancer & Leukaemia in Children) Sargent
Macmillan Cancer Relief
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 Motor Neurone Disease Association
Tak Tent Cancer Support Scotland

Professional Associations

Association for Hospice Management
Association for Palliative Medicine
Association of Chartered Physiotherapists and Occupational Therapists in Palliative Care
Association of Hospice & Palliative Care Chaplains
Association of Hospice & Specialist Palliative Care Social Workers
Association of Voluntary Service Managers
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 2

it said that 'death is a taboo subject'. In relation to this latter point, I think that it is entirely reasonable that healthy people in our society do not want to dwell on death and dying. I do however feel that there is a challenge to clinicians in sensitively raising awareness of palliative care much earlier in the disease trajectory.

I could go on but space is limited and my assessment of the last decade is that the profile of palliative care in Scotland has never been higher than it is today. We owe it however to patients and their families to extol the virtues of palliative care to everyone who will listen and even to those who won't!

Palliative care in Scotland has an exciting future and the Scottish Partnership for Palliative Care is fortunate in the relationship which it enjoys with officials from the Scottish Executive Health Department and the short and effective lines of communication which exist with our Ministers. The Cross Party Group in the Scottish Parliament on Palliative Care, chaired by Michael McMahon, MSP, has shown itself to be an effective forum in which to discuss the key issues in palliative care in Scotland and I hope that it will continue to enjoy the support of our elected representatives.

Finally, I must pay tribute to Pat Wallace and the small (but perfectly formed) staff team who have made it a pleasure and privilege for me to serve on the Partnership Council as a Member, Honorary Treasurer, Deputy Chairman and more recently Chairman.

Scottish Partnership for Palliative Care

Core income and expenditure account for the year ended 31 March 2006

Honorary President		31.03.05	31.03.06
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 2006)			
Professor Frank Clark CBE Chairman	Director, Strathcarron Hospice		
Susan Munroe Deputy Chairman	Director of Patient and Family Services, Marie Curie Cancer Care		
Maria McGill Honourary Treasurer	Chief Executive, Highland Hospice		
Maureen Black	Senior Macmillan Development Officer, Macmillan Cancer Relief		
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		
Dr Elizabeth Ireland	Lead Clinical and General Practitioner, NHS Forth Valley		
Trudy Lafferty	Matron, St Vincent's Hospice		
Kate Lennon	Macmillan Nurse Consultant in Palliative Care, NHS Argyll & Clyde		
Dr Clive Preston	Consultant in Palliative Medicine, NHS Fife		
Dr Catriona Ross	Consultant in Palliative Medicine, St Andrew's Hospice		
Craig Stockton	Chief Executive, Scottish Motor Neurone Disease Association		
Professor John Welsh	Professor, Olav Kerr Chair in Palliative Medicine, University of Glasgow		

Assessors

Nick Brown	Scottish Executive Health Department
Dr Mike Cornbleet	Scottish Executive Health Department
Fiona Warner	Scottish Executive Health Department

Observer

Eve Richardson	Chief Executive, National Council for Palliative Care
----------------	--

Staff

Patricia Wallace Director	Susan Diotaiuti PA to the Director	Stephen Grounds Administrator (until 12.05.05)	Alison Poole BLF Project Manager
Pauline Britton Publications & Group Liaison Officer	Kevin Thomson Policy & Information Officer (until 31.01.06)	Claire Femister Finance & Office Administrator (from 18.07.05)	

Income

Grants for core administration costs:		
- Scottish Executive Health Department	70,000	80,000
- Help the Hospices	1,245	5,000
- Macmillan Cancer Relief	18,540	19,200
- Marie Curie Cancer Care	18,000	18,540
Members subscriptions	60,644	62,486
Interest on deposit	4,549	4,619
Donations	0	10,498
Annual conference	17,550	16,650
	190,528	216,993

Expenditure

Wages and salaries	134,494	151,880
Rent	8,750	9,500
Water rates	0	1,313
Insurance	1,377	1,943
Light and heat	1,044	2,917
Maintenance and repairs	4,137	3,731
Cleaning	2,113	2,213
Stationery	1,562	(785)
Printing and publications	7,717	6,109
Postage	2,632	2,513
Telephone	1,895	1,749
Travel and meetings expenses	3,232	2,740
Annual conference	9,711	10,534
Audit fee	912	950
Professional fees	740	18,675
Recruitment	0	3,116
Depreciation of office equipment	3,329	3,083
Office equipment	145	0
	183,790	222,181
Surplus / (deficit) for the year	6,738	(5,188)
Accumulated surplus brought forward	88,783	95,521
	95,521	90,333

Restricted funds income and expenditure account for the year ended 31 March 2006

Big Lottery Fund Project	2005	2006
	£	£
Balance from previous year	23,308	41,643
Grant received during the year	58,598	82,090
	81,906	123,733
Expenditure during the year	(40,263)	(78,815)
	41,643	44,918

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