

Scottish Partnership for Palliative Care

Annual Report

for the year ended 31 March 2005

Chairman's Report

Education, Ethics & Evidence



Professor Frank Clark CBE, Chairman

As I look back on the last twelve months I have been surprised at how often the three topics of education, ethics and evidence have arisen during the course of our deliberations. This is a time of unprecedented change in the field of healthcare in general and in palliative care in particular and to set these three topics in context it is helpful to reflect on some of the key drivers for change.

- The Kerr Report represents the most far-reaching and comprehensive overview of health and healthcare that I can recall. It has the potential for fundamental changes in how healthcare is delivered and how healthcare professionals operate.
- Community Health Partnerships provide a real opportunity for meaningful patient and public involvement in health matters in a local context but will require new ways of working if they are to achieve their full potential.
- Agenda for Change and the associated Knowledge and Skills Framework provides an explicit link between pay modernisation and sustainable safe and effective changes to service provision which will deliver better care to patients.
- The Liverpool Care Pathway (or similar integrated care pathways) and the Gold Standards Framework have been adopted across the healthcare spectrum at an encouraging rate.
- Local and Regional Managed Clinical Networks in Palliative Care are starting to deliver real benefit.
- Palliative Care Strategies are being developed or revisited throughout Scotland and are now focusing on extending palliative care beyond malignant conditions to embrace a wider spectrum of chronic and progressive illness as well as the delivery of palliative care in a wider range of care settings. How then does this impact on the three topics which I mentioned earlier?

Education: Every one of the key drivers for change mentioned above will demand the full knowledge, understanding and commitment of staff if they are to achieve their full potential. While change for many will represent an opportunity, there will be some staff who will inevitably find the prospect of change daunting or even threatening. It sounds obvious to say that staff are our most valuable resource but it has never been more important to enthuse staff about change and to equip them to deal with it with confidence. It is here that effective education is arguably the key vehicle for success. If our education, training and development providers are to rise to this challenge, however, I would argue that they too must be prepared to change and not simply at the margins. Healthcare providers are becoming increasingly clear about what their expectations of staff are likely to be in the future and it is essential to engage educationalists in this process so that the educational response is appropriate and proportionate to the assessed needs. It will be equally essential to ensure that these educational responses are appropriately quality assured.

New investment will of course be required but I would suggest that there is scope to make significantly better use of current resources. It may be controversial to suggest but education in the broad must become less opportunistic and more strategic if it is to secure the required outcomes and the associated level of investment. Effective education, training and development will help to create the conditions which will enable us to maximise the benefits accruing from such a comprehensive change agenda.

Ethics: It is hard to imagine a time when every aspect of clinical practice has been subject to such intense scrutiny. In recent years we have seen for example

- significant and welcome advances in medical technology
- more challenges to clinical decision making by patients and their families, the public, the media and politicians
- the introduction of a regulatory framework for hospices involving the Scottish Commission for the Regulation of Care (the Care Commission) and the developing role of NHS Quality Improvement Scotland
- clinical practice influenced by an increasing number of guidelines and advisory bodies
- clinical governance as a key component of corporate governance

Whilst all of the foregoing have potential ethical implications for palliative care providers in a general sense there are some challenging issues which have specific resonance for us. These include:

- draft legislation including 'The Assisted Dying Bill' sponsored by Lord Joffe and the proposed 'Dying with Dignity Bill' from Jeremy Purvis, MSP which has been the subject of recent consultation
- withdrawing and withholding life prolonging treatment
- medical futility
- genetic factors
- Do Not Resuscitate decisions
- informed consent
- Advance Directives/Living Wills.

The list goes on but even these examples highlight the significant ethical (and often moral) challenges confronting doctors, nurses, allied health professionals and others often on a daily basis. One must acknowledge the 24 hour access to ethical advice from a number of national bodies, however I sense a growing need for such advice to be available at a local level with close links to both clinical ethics committees and to the wider clinical governance process.

Views on the appropriate level of ethical advice will I am sure differ but I am equally confident that the need for such advice in today's clinical society will grow.

Evidence: I have for a long time held the view that the evidence base for palliative care in contrast to many other areas of clinical practice is relatively underdeveloped. For obvious reasons we cannot produce the grade of evidence which can be generated by Randomised Control Trials but we do need to adopt a more positive mindset towards the evidence produced from qualitative research. In the same vein greater value needs to be placed on qualitative research by our universities and related bodies. I would argue that if the research methodology is soundly based and the analysis and interpretation of the data is carried out in a robust manner then qualitative research can provide powerful evidence of our contention that palliative ...

Continued on page 5

Director's Report

1 April 2004 to 31 March 2005

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. Its charitable objects are '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'.

During 2004-2005, these objects translated into a challenging programme of activities, consolidating and extending the work of the previous year. With a growing emphasis on the palliative care needs of those with progressive non-malignant conditions alongside the more traditional focus on improving palliative cancer care, the Partnership's programme of work has been designed to inform new policy developments and to contribute to the implementation of health strategies to ensure the future provision of appropriate palliative care to all who need it.

Membership structure

The Partnership continues to provide a national palliative care focus and an effective two-way channel of communication between those involved in planning or providing palliative care at local and regional level and national bodies such as the Scottish Executive Health Department, the Scottish Cancer Group, NHS Quality Improvement Scotland, NHS Education for Scotland and the Scottish Commission for the Regulation of Care (Care Commission).

Recent NHS restructuring and the abolition of NHS Trusts meant that in order to maintain this function, the Partnership had to determine an alternative means of securing appropriate NHS representation to its constituency groups. Following widespread consultation with NHS Boards, existing Partnership constituency groups and local and regional palliative care Managed Clinical Networks, proposals whereby mainland Boards would nominate four and Island Boards two member representatives were agreed at the Annual General Meeting in September 2004. Non NHS representation remained unchanged.

Regional constituency groups

Changes in group representation were successfully implemented, and have resulted in increasingly effective relationships in each of the three regions between the Partnership's Regional Groups, Regional Cancer Networks and local and regional palliative care Managed Clinical Networks. Arrangements remain flexible, and are adapted in each area in consultation with those concerned to meet local needs and circumstances.

In the **West of Scotland**, for example, where the Partnership had previously facilitated the starting up of the regional palliative care Managed Clinical Network, it has been agreed following further consultation to hold joint meetings of the MCN steering group and the Partnership West Regional Group. The first of these was held in November 2004, and was felt to be a productive development. In the **North** and **South East of Scotland**, the Partnership Regional Groups provide a useful regional forum, in the absence of a regional palliative care network, for the bringing together of local palliative care Managed Clinical Networks. In the North, meetings are held by video-conference, linking representatives from Orkney, Shetland and the Western Isles with colleagues in Highland, Grampian and Tayside.

As NHS structures and strategies continue to evolve, the Scottish Partnership for Palliative Care will remain flexible in adapting and working with any new arrangements and

groupings which arise, and will continue to take a lead in drawing together information and issues from local and regional areas to inform the development of appropriate national policies.

National constituency groups

The Partnership's three national constituency groups have also been particularly active in the past year. The **National Charities Group**, having extended its membership in recent years to embrace national organisations representing the needs of people with progressive non-malignant conditions, heard and discussed presentations from Alzheimer Scotland, Parkinson's Disease Society and Scottish Motor Neurone Disease Association as well as from Cancer BACUP, Breast Cancer Care Scotland and Tak Tent Cancer Support Scotland. The group also considered issues such as user involvement within the cancer agenda and future projected need for palliative care in care homes for non-cancer patients.

The **Scottish Hospices Forum** continued to build stronger and more effective working relationships with the Care Commission, with representatives of the Forum participating in Care Commission advisory working groups, and Care Commission representatives participating in meetings of the Forum. Initial difficulties over Care Commission registration and inspection of hospice home care services were resolved in a series of special meetings. The Forum considered a range of additional issues in hospice management at their regular meetings, including inspection methodology, measurability of standards, patient surveys and Agenda for Change, as well as keeping in touch with international and UK palliative care via input from Help the Hospices.

The **Specialist Palliative Care Group** continues to work with the Scottish Ambulance Service on the new Clinical Care Standard 2 - Cancer and Palliative Care. Concerns raised by the Group over ambulance transfers for hospice patients were also addressed by the Scottish Ambulance Service. Among other activities, the Group maintained contact with the Chief Pharmacist over the issue of disposal of controlled drugs, wrote to the Scottish Executive Health Department to seek guidance on cardiopulmonary resuscitation as a Human Rights issue, received regular reports on the Gold Standards Framework Scotland from its representative on the steering group, considered the new GMS contract and the issues of day and night palliative care in the community, sent representatives to events on chronic pain and on the Adults with Incapacity Act, participated in consultation on the Assisted Dying for the terminally ill Bill in the House of Lords, and initiated the

Scottish Partnership for Palliative Care response to the Dying with Dignity draft bill in the Scottish Parliament.

Short-life working groups

In addition to the constituency groups, two short-life working groups also continued their activities throughout the year.

The **Care Homes working group**, chaired by Susan Munroe and comprising representatives from the Care Commission, care homes, health and social care and palliative care continued its task at the request of the Scottish Executive to develop a set of national standards for the delivery of non-specialist palliative care in care homes. Based on National Care Standards, these standards have been devised in the form of good/best practice statements, and have now been circulated widely in draft form for consultation. The final version is expected to be launched later in 2005.

The **short-life working group on palliative care and end stage heart failure** also set up at the request of the Scottish Executive, comprises representatives from fields including palliative care, cardiac care, primary care and medicine for the elderly. Chaired by Dr Martin Leiper, the group has worked to identify and explore key issues and to develop key recommendations in areas such as communication, symptom management, practical and psychosocial support and end-of-life care, which will form the focus of the final report. It is hoped that a consultation draft, titled 'Living and Dying with Heart Failure', will be completed for circulation in autumn 2005.

Big Lottery Fund Project

The Partnership's three year Big Lottery Fund Project, '**increasing access to palliative care for people with life-threatening conditions other than cancer**' has



now completed its first year and successfully met all its targets to date. In addition to the project steering group, a subgroup of the Partnership Council, two project reference groups have been established to advise and to monitor progress. One, the professional reference group, is a multi-professional group and includes those working with conditions covered by the project such as cystic fibrosis, dementia, heart failure, motor neurone disease, muscular dystrophy, multiple sclerosis, Parkinson's

disease and renal failure. The other, the user reference group, comprises patients, carers and past carers representing a range of the same conditions. Both groups have made significant contributions to the project and informed the development of the first round of consultation. Over 1000 questionnaires have now been distributed to generic health and social care professionals, and a further 1000 to patients and informal carers. First indications are that the response rate is well above target and that the information gained will be extremely useful in developing further stages of the project's objectives, as well as contributing to the ongoing mapping of palliative care needs and services in Scotland.

Publications

During the year the Partnership continued to produce regular editions of its Update newsletter and of Courses and Conferences, its digest of current palliative care courses and events in Scotland. Both of these are circulated widely within member organisations and beyond. A report of the November 2003 annual conference **Beyond the randomised trial: evidence and effectiveness in palliative care** was also produced. All our publications are available on the Partnership's website www.palliativecarescotland.org.uk which also contains information about palliative care services in Scotland and links to other useful websites.

Annual conference

The 200 delegates at the 2004 Annual conference were encouraged to think of 'moving beyond the comfort zone' and invited by Honorary President Dr Derek Doyle to consider entering new realms of professional discomfort in order to learn new approaches and to determine how best to meet the needs of patients. Professor Nora Kearney's presentation challenged assumptions about the extent to which cancer patients are actually involved in their own care, while Professor John Atkinson

explored the difficulties experienced by some sectors of the population in accessing palliative care. A range of workshops also explored different issues.

Scottish Parliament

Links with the Scottish Parliament continued throughout the year, with the Partnership continuing to provide the secretariat for the Cross Party Group on Palliative Care. The meeting in June 2004 focussed on lymphoedema services in Scotland, and met with a positive response from MSPs present. A number of issues were identified to be taken forward as appropriate by NHSQIS, the Lymphoedema Practitioners Group and the Scottish Partnership for Palliative Care. In November 2004, Professor Frank Clark and Dr Stephen Hutchison led a well-received presentation and discussion on issues raised by the Assisted Dying for the Terminally Ill Bill in the House of Lords, while in March 2005 a joint meeting was held with the Cross Party Group on Cancer.

Also in March 2005, the Partnership responded to the consultation on the draft bill 'Dying with Dignity' proposed by Jeremy Purvis MSP by holding a day conference for member representatives to discuss the implications of the proposed legislation. There was a clear consensus in opposition to the bill, and a detailed consultation response was submitted.

UK liaison

The Partnership continues to value its liaison with UK bodies such as the National Council for Palliative Care, who are represented as an observer on the Partnership Council, and Help the Hospices, who participate in the Scottish Hospices Forum. Much useful cross-fertilisation occurs as a result of these, among other, on-going links.

Funding

The continuing support of the Partnership's grant funders, the Scottish Executive Health Department, Macmillan Cancer Relief, Marie Curie Cancer Care and Help the Hospices, and of all its member organisations is gratefully acknowledged. In all cases, financial contributions are matched by equally generous contributions of good will, time, effort and expertise, without which none of the work here reported would be possible. Thank you all.

Scottish Partnership for Palliative Care Member Organisations 2004-2005

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's Hospice
St Vincent's Hospice
Strathcarron Hospice

National Charities

Alzheimer Scotland - Action on Dementia
Breast Cancer Care Scotland
CancerBACUP Scotland
Macmillan Cancer Relief
Marie Curie Cancer Care
Multiple Sclerosis Society Scotland
Pain Association Scotland
Parkinson's Disease Society
Roy Castle Lung Cancer Foundation
Sargent Cancer Care for Children
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
INVOLVE
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

... care can and does make a significant difference to the quality of the lives of patients and their families.

If we are so confident that what we do makes such a difference why should we bother with research based evidence? Quite simply palliative care is no different to any other aspect of clinical practice and if we operate in a health society which is becoming increasingly evidence based then I can see no compelling reason for us to be exempt however difficult it may be to conduct research in the field of palliative care.

We must remember that resource investment decisions are hard for our legislators and for NHS Boards but it is not particularly persuasive to say that good palliative care can really result in 'a better death'. This is particularly so when the benefits of investment in other aspects of clinical care are more obvious and more increasingly evidence based. The challenge for us all is to use the emerging networks to develop robust and relevant research proposals so that we can prove what we believe ie that palliative care does make a significant and beneficial difference.

The importance of these topics has been recognised by the Partnership and each one features prominently in the programme for the 2005 Annual Conference. There will, as I have suggested, be a wide range of views on these topical and sometimes controversial issues and I look forward to extending the debate at the Conference.

In conclusion I must pay tribute to Pat Wallace and the small team at the Partnership office who have worked so hard over the last year and who have supported me so well in my role as Chairman.

Scottish Partnership for Palliative Care

Core Income and Expenditure Account for the year ended 31 March 2005

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 2005)

Professor Frank Clark CBE
Chairman

Director,
Strathcarron Hospice

Susan Munroe
Deputy Chairman

Caring Services Manager Scotland,
Marie Curie Cancer Care

Ian Gibson
Honourary Treasurer

Director for Scotland and Northern Ireland,
Macmillan Cancer Relief

Margaret Dunbar

Director of Nursing,
St Columba's Hospice

Vicky Freeman

Cancer Services Programme Manager,
NHS Dumfries & Galloway

Joan Hemphill

Clinical Director,
Prince & Princess of Wales Hospice

Iain Laidlaw

Chief Executive,
Prince & Princess of Wales Hospice

Dr Mhoira Leng

Consultant in Palliative Medicine,
Grampian University Hospitals NHS Trust

Kate Lennon

Macmillan Nurse Consultant in Palliative Care,
NHS Argyll & Clyde

Maria McGill

Chief Executive,
Highland Hospice

Dr Clive Preston

Consultant in Palliative Medicine,
Fife Palliative Care Services

Dr James Rodgers

Consultant in Palliative Medicine,
NHS Borders

Dr Catriona Ross

Consultant in Palliative Medicine,
St Andrew's Hospice

Robert Shorter

Planning Manager,
Lanarkshire Primary Care NHS Trust

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

Observer

Eve Richardson

Chief Executive,
National Council for Palliative Care

Staff

Patricia Wallace
Director

Susan Diotaiuti
PA to the Director

Stephen Grounds
Administrator

Pauline Britton
Publications &
Group Liaison Officer

Kevin Thomson
Policy & Information
Officer

Alison Poole
BLF Project Manager

	31.03.04	31.03.05
	£	£
Income		
Grants for Core Administration Costs:		
- Scottish Executive Health Department	64,000	70,000
- Help the Hospices	0	1,245
- Macmillan Cancer Relief	18,000	18,540
- Marie Curie Cancer Care	15,000	18,000
Subscriptions	58,799	60,644
Interest on Deposit	3,139	4,549
Annual Conference	15,186	17,550
	174,124	190,528
Expenditure		
Wages and Salaries	122,989	134,494
Rent	8,000	8,750
Insurance	744	1,377
Light and Heat	1,498	1,044
Upkeep of Property	1,938	4,137
Cleaning	2,164	2,113
Stationery	3,751	1,562
Printing and Publications	9,537	7,717
Postage	3,689	2,632
Telephone	2,003	1,895
Travel and Meetings Expenses	2,674	3,232
Annual Conference	11,436	9,711
Audit Fee	885	912
Professional Fees	535	740
Recruitment	1,613	0
General Expenses	163	0
Depreciation of Office Equipment	2,948	3,329
Office Equipment	2,257	145
	178,824	183,790
Surplus for the Year	(4,700)	6,738
Accumulated Surplus Brought Forward	93,483	88,783
	88,783	95,521

Restricted Funds Income and Expenditure Account for the year ended 31 March 2005

	2004	2005
	£	£
Big Lottery Fund Project		
Balance from previous year	0	23,308
Grant received during the year	38,114	58,598
	38,114	81,906
Expenditure during the year	14,836	40,263
	23,308	41,463

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.