

Chairman's Report

Palliative care development in Scotland: a challenging agenda



Professor Frank Clark CBE, Chairman

When you are caught up in the maelstrom of the 'here and now' it can sometimes be difficult to take time out to reflect on the high level challenges confronting those involved in planning and delivering palliative care. Last year I had the opportunity to address the Annual General Meeting of the Cross Party Group in the Scottish Parliament on Palliative Care and I chose as my theme 'Palliative Care Development in Scotland: A Challenging Agenda' since I wanted our legislators to have a wider perspective on the key issues confronting us. Where then do these challenges lie?

Palliative care in chronic and progressive illness

Many people with chronic and progressive illnesses face the same issues as those with cancer ie lack of an available cure, diminished quality of life and a shorter life span. Quite often these conditions will develop at a younger age and people will live longer with the condition. Whilst they are generally physically well cared for their palliative care needs are often poorly addressed, which is in contrast to those with a malignant condition. While services are developing much remains to be done to redress the current inequity of service provision.

Palliative care in multiple care settings

For a wide range of legitimate reasons the pattern of healthcare provision in Scotland is undergoing an unprecedented level of change. The future will see fewer acute hospitals with shorter length of stay and more rapid

throughput requiring more effective pre-admission and post discharge planning and management. Developments will take place around the role of intermediate care, community hospitals, primary care and importantly the care home sector. If we are to embrace a wider range of conditions then palliative care will require to be delivered in a much wider range of settings across the care spectrum. The role of specialist palliative care providers will continue to evolve and in addition to direct care delivery there will be an increasing emphasis on enabling, facilitating and supporting the delivery of good quality palliative care by generalists across the care spectrum.

Resourcing palliative care

The challenges above will only be met if urgent attention is given to more effective workforce planning. Serious recruitment difficulties exist with medical nursing and allied health professionals, all of whom will be required to deliver effective palliative care in a multiplicity of settings to patients with a wider range of conditions. Appropriate levels of funding will of course be needed and we ask only that palliative care is given its place alongside other developments when investment priorities are being considered.

Inter agency working

Many of the challenges in palliative care lie at the interfaces of care, and effective inter agency working will be crucial if we are to respond to the rapidly developing agenda. Operational collaboration is generally good but greater clarity is needed around the roles and responsibilities of those involved in policy development and implementation.

Palliative care education

One of the keys to effective management of change is to identify and respond appropriately to the education and development needs of those responsible for service delivery. It is imperative that education is not regarded as an optional extra to be lifted or laid as time or finance allows and it has to be accepted that maintaining practitioners at the leading edge of thinking and practice is fundamental to good care delivery. Against this backdrop the challenge will be to develop a Scotland wide framework within which there will be equitable access to educational opportunities of a uniformly high standard.

Palliative care for children and young people

Palliative care for children in Scotland has developed well in recent years and the second children's hospice at Balloch will further enhance provision. The position of young people in the transition from childhood to adulthood presents particular challenges which are not always reflected in the planning and delivery of services. Although in relative terms small in number the particular needs of young people and their families must be given proper consideration.

Public awareness/expectations

It's a fact that the term palliative care is poorly understood but despite this we must not presume that the public in general particularly want to be educated about it. For example faced with the choice in a GP waiting room of a range of magazines or a leaflet on palliative care it is fairly certain what most people would opt to read. This poor understanding can sadly lead to low expectation with all that this entails. The challenge therefore is to provide information tailored to the needs of the individual patient and their family in appropriate formats and at all key stages in the disease trajectory from diagnosis onwards.

Many will say that these are not the only challenges facing palliative care and of course this is correct. There are other challenges not least of which is the need to develop more robust evidence to prove in this evidence based clinical society that good palliative makes a beneficial difference. The challenges which I have highlighted I would argue do set a broad context within which to view the future development of palliative care. If we don't respond to these challenges then palliative care will not develop as it should and we will fail those who rely on us most, our patients and their families. This is an exciting time for palliative care and one in which every challenge presents a set of opportunities of which we must take advantage.

Director's Report

1 April 2003 to 31 March 2004

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.

2003-2004 was a full and productive year with the Partnership continuing to expand its activities to include a range of work which will contribute to the implementation of health strategies to ensure that appropriate standards of palliative care are available in the future to all who need it. In addition to the usual meetings of Council and constituency groups, production of publications and activities such as conferences, consultations and liaison with key national bodies, two short-life expert working groups were set up at the request of the Scottish Executive Health Department to produce recommendations on palliative care for people with heart failure and on national standards for palliative care in care homes and planning for a Scotland-wide palliative care mapping exercise was begun at the request of the Chief Medical Officer. Funding was also secured from the New Opportunities Fund for a three-year Scotland-wide project to explore ways of meeting the palliative care needs of people with a range of progressive non-malignant conditions. A selection of the year's key achievements and activities are summarised below.

Core activities

The Partnership provides a 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, and the Scottish Commission for the Regulation of Care (Care Commission), all of whom look to the Partnership for consultation and guidance. There is a link to the Scottish Parliament via the Partnership's secretariat of the Cross Party Group on Palliative Care, while at regional level the Partnership is increasingly involved in strengthening links with and between local and regional palliative care Managed Clinical Networks and with Regional Cancer Networks. UK wide liaison is maintained through ongoing links with bodies such as the National Council for Hospice and Specialist Palliative Care Services, the Cicely Saunders Foundation, Help the Hospices, Macmillan Cancer Relief, and Marie Curie Cancer Care.

Constituency groups

Throughout the year the Partnership's network of regional and national groups maintained a full programme of activities.

Regional groups discussed a wide range of issues and heard presentations from visiting speakers on topics such as the Gold Standards Framework, the Cancer Pain Integrated Care Pathway Project, lymphoedema, heart failure, motor neurone disease and multiple sclerosis.

A number of new member organisations providing support for people with specific non-malignant conditions were welcomed to membership of the Partnership and greatly enhanced the activities of the **National Charities Group**. Many of these, and others, were also involved in consultation in preparation of the Partnership's New Opportunities Fund bid.

The **Scottish Hospices Forum** addressed the twin challenges for voluntary hospices of meeting the requirements of the NHS Quality Improvement Scotland Clinical Standards for Specialist Palliative Care and the National Care Standards for Hospice Care monitored under the Regulation of Care (Scotland) Act 2001 by the Care Commission. The Forum worked closely with representatives of the Care Commission throughout the year, and was also grateful for NHS input and support in exploring the implications for hospices of Agenda for Change.

The **Specialist Palliative Care Group** considered a range of issues including cardiopulmonary resuscitation, palliative care for people with heart failure and disposal of controlled drugs. A meeting was held with the Chief Pharmacist at the Scottish Executive Health Department to discuss the latter, and the group submitted a response to the Shipman Inquiry. Representatives of the Scottish Ambulance Association also attended meetings of the group to consult on their new draft Clinical Care Standards for Cancer and Palliative Care.

NHS restructuring and the abolition of NHS Trusts meant that the Partnership had to determine an alternative means of securing appropriate NHS representation to its constituency groups, and following consultation with NHS Boards and existing groups, proposals whereby mainland Boards would nominate four and Island Boards two member representatives were agreed to be put to the AGM in September 2004.

Clinical standards for specialist palliative care

2003-2004 saw the conclusion of the first round of visits by peer review teams of the Clinical Standards for Specialist Palliative Care, developed jointly by the former Clinical Standards Board for Scotland and the Scottish Partnership for Palliative Care, and the launch by NHS Quality Improvement Scotland of the first National Overview and Local Reports. The Partnership chairman, Professor Frank Clark CBE, was delighted to have the opportunity to join Lord Patel, chairman of NHSQIS and Professor John Welsh, chairman of the review group, on the platform at the launch in January 2004 to emphasise the value of the review process and the significance of the report for the future development of palliative care in Scotland.

Annual conference and AGM

Another highlight of the year was the Partnership's annual conference in November 2003, 'Beyond the randomised trial: evidence and effectiveness in palliative care', which attracted over 200 delegates. The conference was chaired by Honorary President-elect Dr Derek Doyle OBE, and the AGM included an address by the retiring Honorary President Sir Kenneth Calman KCB, whose commitments happily allow him to take over the role of Honorary Vice-President.



New Opportunities Fund
LOTTERY FUNDED

New Opportunities Fund Award

In August 2003 the Partnership was awarded a New Opportunities Fund award of £231,138 over three years for a new project aiming to improve access to palliative care for people with life-threatening conditions other than cancer. The project aims to:

- find out what are the palliative care needs of people with a range of non-malignant progressive diseases and to promote wider recognition of these
- develop an understanding of some of the barriers involved in the failure of these groups to access appropriate palliative care
- identify possible ways of overcoming the barriers and meeting the needs identified and
- promote the integration of palliative care principles in the care of people with a range of non-malignant progressive conditions.

A full-time Project Manager took up post in January 2004, reporting to the Partnership Director and the Project Steering group, a sub-committee of the Partnership Council. Contact has been established as widely as possible with others engaged in similar work to avoid duplication and to ensure co-operation and collaboration and the project will culminate in a final conference and report at the end of 2006.

Heart failure working group

The short-life working group set up at the request of the Scottish Executive to take forward the recommendation of the Coronary Heart Disease and Stroke Strategy for Scotland that palliative care should be made available to people with end-stage heart failure met for the first time in June 2003 with a remit to:

- identify key issues to be considered in making palliative care available to people with cardiac failure
- produce guidelines for good practice and make recommendations on service provision
- circulate and encourage adoption of these via cardiac and palliative care MCNs.

The group, comprising representatives from fields including palliative care, cardiac care, primary care and medicine for the elderly, hopes to complete its work early in 2005.

Care Homes working group

A further short-life working group, including representatives of the Care Commission, was set up in the autumn of 2003 to develop national standards for non-specialist palliative care in care homes. These will be launched during 2005 and will:

- apply to all care homes
- be consistent with the general approach of the Care Commission and relate to the existing national care standards
- take the form of national good/best practice standards in basic palliative care.

Publications

A range of publications was produced during the year, including the Partnership's regular *Update* newsletter, a report of the November 2002 annual conference *Rethinking palliative care: an opportunity to explore new challenges* and *Public awareness of palliative care*, a report of the findings of the first national survey in Scotland into public knowledge and understanding of palliative care, commissioned by the Partnership. There were also two joint publications: *Palliative care in*

community hospitals in Scotland: a framework for good practice 2003 produced with the Scottish Association of Community Hospitals and *Palliative care and people with learning disabilities*, a report of a joint conference in February 2003 held by the Scottish Partnership for Palliative Care, the Glasgow-based learning partnership Common Knowledge and St Columba's Hospice.

Scottish Parliament

The Partnership continued to provide the secretariat for the Cross Party Group on Palliative Care in the Scottish Parliament. The year's programme included a presentation on delivering palliative care at home, after which a palliative care motion was put forward by Michael McMahon MSP, convener of the Cross Party Group on Palliative Care in the Scottish Parliament, and a joint meeting with the Cross Party Group for Cancer in the Scottish Parliament, following which a number of questions on palliative care were put to the Scottish Parliament by Kenneth McIntosh MSP, joint convener of the Cross Party Group on Cancer in the Scottish Parliament. The Cross Party Group for Palliative Care AGM was addressed by Partnership chairman Professor Frank Clark - the key points of his presentation are outlined at the start of this report.

Funding

As usual, the Partnership expresses its thanks to all its members and funders for their continued support throughout the year. It is only through the continued contribution of our grant funders, the Scottish Executive Health Department, Macmillan Cancer Relief, Marie Curie Cancer Care and Help the Hospices, (who underwrite part of any annual deficit) and of our member organisations through their subscriptions, support of our conferences, and generous gifts of time and expertise, that we are able to pursue with them our joint aims for palliative care and those who need it.



Scottish Partnership for Palliative Care Member Organisations 2003-2004

NHS Boards

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

NHS Trusts

Argyll & Clyde Acute Hospitals NHS Trust
Ayrshire & Arran Acute Hospitals NHS Trust
Ayrshire & Arran Primary Care NHS Trust
Borders General Hospital NHS Trust
Borders Primary Care NHS Trust
Dumfries & Galloway Acute & Maternity
Hospitals NHS Trust
Dumfries & Galloway Primary Care NHS Trust
Fife Acute Hospitals NHS Trust
Fife Primary Care NHS Trust
Forth Valley Acute Hospitals NHS Trust
Forth Valley Primary Care NHS Trust
Grampian Primary Care NHS Trust
Grampian University Hospitals NHS Trust
Greater Glasgow Primary Care NHS Trust
Highland Acute Hospitals NHS Trust
Highland Primary Care NHS Trust
Lanarkshire Acute Hospitals NHS Trust
Lanarkshire Primary Care NHS Trust
Lomond & Argyll Primary Care NHS Trust
Lothian Primary Care NHS Trust
Lothian University Hospitals NHS Trust
North Glasgow University Hospitals NHS Trust
Renfrew & Inverclyde Primary Care NHS Trust
South Glasgow University Hospitals NHS Trust
Tayside Primary Care NHS Trust
Tayside University Hospitals NHS Trust
West Lothian Healthcare NHS Trust
Yorkhill NHS Trust

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

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)

Scottish Partnership for Palliative Care

Detailed Core Income and Expenditure Account for the year ended 31 March 2004

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 2004)

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

Aileen Anderson

Director of Nursing & Hospice Services,
Ayrshire Hospice

Jo Bennett

General Manager,
St Columba's Hospice

Joan Hemphill

Clinical Director,
Prince & Princess of Wales Hospice

Dr Mhoira Leng

Consultant in Palliative Medicine,
Grampian University Hospitals NHS Trust

Maria McGill

Chief Executive,
Highland Hospice

Elaine Peace

Macmillan Lead Cancer Nurse,
NHS Borders

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

Morag Sinclair

Senior Nurse Manager,
South Glasgow University Hospitals 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

Dr Mike Cornbleet
Will Scott

Scottish Executive Health Department
Scottish Executive Health Department

Observer

Eve Richardson

Chief Executive, National Council for
Hospice & Specialist Palliative Care Services

Staff

Patricia Wallace
Director

Susan Diotaiuti
PA to the Director

Stephen Grounds
Administrator

Pauline Britton
Publications &
Group Liaison Officer

Kevin Thomson
Policy & Information
Officer
(from January 2004)

Alison Poole
NOF Project Manager
(from January 2004)

	31.3.03	31.03.04
	£	£

Income

Grants for Core Administration Costs:

- Scottish Executive Health Department	58,000	64,000
- Help the Hospices	1,500	0
- Macmillan Cancer Relief	18,000	18,000
- Marie Curie Cancer Care	15,000	15,000

Subscriptions	58,371	58,799
Interest on Deposit	2,834	3,139
Conference Surplus	4,164	3,750
Mental Health Conference Surplus	134	0
Patient Held Records Project	1,305	0
Community Fund Grant	506	0

	159,814	162,688
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Expenditure

Wages and Salaries	107,756	122,989
Rent	8,000	8,000
Insurance	763	744
Light and Heat	945	1,498
Upkeep of Property	2,832	1,938
Cleaning	2,095	2,164
Stationery, Printing and Publications	14,648	13,288
Postage and Telephone	5,415	5,692
Travel and Meetings Expenses	4,133	2,674
Audit Fee	844	885
Legal Fees	1,022	535
Recruitment	6,389	1,613
Membership Fees	225	0
General Expenses	0	163
Depreciation of Office Equipment	819	2,948
Office Equipment	0	2,257

	155,886	167,388
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Deficit for the Year	3,928	(4,700)
Accumulated Surplus Brought Forward	89,555	93,483

	93,483	88,783
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Copies of the full audited accounts for the year (including restricted funding from the New Opportunities Fund), 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.

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**Scottish Partnership
for Palliative Care**

Annual Report

for the year ended 31 March 2004

