

**Cross-Party Group in the Scottish Parliament
on Palliative Care**

Convener
Michael McMahon MSP

Vice Convener
Vacant

Secretary
Patricia Wallace

**Approved minute of the meeting of the Cross-Party Group
on Palliative Care in the Scottish Parliament**

**Wednesday 6 June 2007 at 5.45pm
Committee Room 1, Scottish Parliament Headquarters**

Present:

Michael McMahon MSP (convenor)	Belshill & Hamilton
Roseanna Cunningham MSP	Perth
Jamie McGrigor MSP	Highlands and Islands
Douglas Pattullo	Office of Jamie McGrigor MSP
Philip Atkinson	Scottish Health Magazine
Dr Paul Baughan	NHS Forth Valley
Dr Rosaleen Beattie	Scottish Executive Health Department
Dr Pat Carragher	Children's Hospice Association Scotland
Rev Stuart Coates	Strathcarron Hospice
Margaret Colquhoun	St Columba's Hospice, Edinburgh
Lisa Dunbar	Western General Hospital
Margaret Dunbar	St Columba's Hospice
Dr Rosalie Dunn	NHS Lanarkshire
Shirley Fife	NHS Lothian
Tom Gault	St Andrew's Hospice
Linda Kerr	NHS Ayrshire & Arran
John Macgill	British Psychological Society
Dorothy McElroy	Ardgowan Hospice
Maria McGill	Highland Hospice
Elaine MacLean	Care Commission
Irene McKie	Strathcarron Hospice
Clare Murphy	St Margaret of Scotland Hospice
Professor Scott Murray	University of Edinburgh
Dr Euan Paterson	NHS Greater Glasgow & Clyde
Ros Scott	CHAS
Robert Shorter	NHS Lanarkshire
Craig Stockton	Scottish MND Association
John Sweeney	Cancerbackup Scotland
Hazel Taylor	West of Scotland MCN for Palliative Care
Elizabeth Thomas	St Margaret of Scotland Hospice
Anne Thomson	Scottish Huntington's Association
Margaret White	Marie Curie Cancer Care
Anne Willis	Marie Curie Hospice Edinburgh
Dan Wynn	General Medical Council

In attendance:

Pauline Britton	Scottish Partnership for Palliative Care
Rebecca Patterson	Scottish Partnership for Palliative Care
Patricia Wallace	Scottish Partnership for Palliative Care

Apologies:

Jackie Baillie MSP	Dumbarton
Richard Baker MSP	North East Scotland
Bill Butler MSP	Glasgow Anniesland

Apologies:	Cathie Craigie MSP	Cumbernauld & Kilsyth
	Bruce Crawford MSP	Minister for Parliamentary Business
	Bob Doris MSP	Glasgow
	Alex Fergusson MSP	Presiding Officer
	Karen Gillon MSP	Clydesdale
	Marilyn Glen MSP	North East Scotland
	Patrick Harvie MSP	Glasgow
	Adam Ingram MSP	Minister for Children and Early Years
	Johann Lamont MSP	Glasgow Pollock
	John Lamont MSP	Roxburghe & Berwickshire
	Richard Lochhead MSP	Cabinet Secretary for Rural Affairs and the Environment
	Kenny MacAskill MSP	Cabinet Secretary for Justice
	Liam McArthur MSP	Orkney
	David McLetchie MSP	Edinburgh Pentlands
	Des McNulty MSP	Clydebank & Milngavie
	Nanette Milne MSP	North East Scotland
	Cathy Peattie MSP	Falkirk East
	Jeremy Purvis MSP	Tweeddale, Ettrick and Lauderdale
	Elaine Smith MSP	Coatbridge & Chryston
	Jamie Stone MSP	Caithness, Sutherland and Easter Ross
	John Swinney MSP	Cabinet Secretary for Finance and Sustainable Growth
	Dr T F Benton	St Columba's Hospice
	Dr Duncan Brown	St Columba's Hospice
	Gill Chadwick	NHS Western Isles
	Richard Dimelow	Scottish Executive Health Department
	Dr Cameron Fergus	NHS Borders
	Ellen Finlayson	CLIC Sargent
	Anne Gourlay	NHS Tayside
	Anna Grady	Marie Curie Hospice, Glasgow
	Gillian Hailstones	St Margaret of Scotland Hospice
	Wilma Halley	NHS Highland
	Mark Hazelwood	MS Society Scotland
	Dr Elizabeth Ireland	NHS Forth Valley
	Dr David Jeffrey	NHS Borders
	Trudy Lafferty	St Vincent's Hospice
	Kirsty Leavey	Strathcarron Hospice
	Dr Sheila McGettrick	NHS Greater Glasgow & Clyde
	Marie McGill	Scottish Huntingdon's Association
	Edward McGuigan	St Margaret's of Scotland Hospice
	Dr David Oxenham	Marie Curie Hospice Edinburgh
	Dr Clive Preston	NHS Fife
	Anne Robb	NHS Tayside
	Dr Catriona Ross	St Andrew's Hospice
	Linda Smith	NHS Lothian
	Elaine Stevens	RCN Palliative Nursing Group
	Dr Chris Sugden	St Andrew's Hospice
	Debbie Thomson	Cancer Link Aberdeen & North (CLAN)
	Lesley Whitelaw	Strathcarron Hospice

1. Welcome and apologies

Michael McMahon MSP welcomed attendees to the first cross-party group meeting in this parliamentary session. He assured those present that he continues to be committed to the group, thanked Roseanna Cunningham MSP for her continuing commitment and introduced Jamie McGrigor, Highlands and Islands MSP. Michael explained that he expected that, given the commitment of the MSPs present, and the interest of those MSPs unable to attend, it should be possible for the group to be officially re-constituted following completion of the appropriate documentation.

2 AGM

The annual general meeting took place including election of office-bearers for 2007 – 08. (Details of this meeting are recorded as a separate minute.)

3. Minutes of meeting of Wednesday 7 March 2007

The minute of the previous meeting held on Wednesday 7 March 2007 was adopted as a true record.

4. Matters arising

4.1 Prescription charges (item 3.1)

Michael McMahon updated the group that in April the Scottish Executive published a *Review of NHS Prescription Charges and Exemption Arrangements in Scotland: Analysis of Responses Received*. This report presents the findings of a public consultation which took place between January and June 2006, to inform the Scottish Executive's *Review of NHS Prescription Charges and Exemption Arrangements in Scotland*.

This report is available on the Scottish Executive website. The main findings included:

- strong support for all people with long-term medical conditions obtaining exemption from prescription charges, with almost nine out of ten people endorsing this suggestion.
- While the majority supported diverting money from other areas of government spending in Scotland to pay for the extension of free prescriptions, it was clearly felt that this should not come from NHS budget allocations. Free prescriptions should not, in the public view, be provided at the expense of other aspects of NHS funding and performance.

Roseanna Cunningham added that the SNP made a manifesto commitment to extending free prescriptions to more people with chronic conditions, and though currently there are no firm time commitments, she expects that there will be movement on this issue in the near future.

ACTION: This is an ongoing issue and will remain on the agenda.

PB / PW

4.2 Lymphoedema update (item 3.2)

Michael McMahon updated the group. As was reported at the last meeting, the International Consensus Document *Best practice for the*

management of lymphoedema was launched at the conference of the British Lymphoedema Society in October last year. NHS QIS plans to look at this document with a view to issuing recommendations regarding its adoption in Scotland. It is anticipated this work will be completed by Autumn this year.

ACTION: This is an ongoing issue and will remain on the agenda

PB / PW

4.3 Modernising Medical Careers (MMC) (item 3.5)

The Partnership sent a letter to the Chief Medical Officer in February, highlighting concerns expressed by the Scottish Hospices Forum, Specialist Palliative Care Group and Cross Party Group about the implications of MMC for palliative medicine in Scotland, and offering the Partnership's support in resolving these issues.

The Chief Medical Officer has since sent the Partnership a detailed reply, responding to each specific point in turn.

ACTION: A copy of the letter from the CMO will be circulated with the minute from this meeting (appendix 1). There will be an opportunity at the next meeting of the group to raise any matters arising from this letter.

PB

4.4 Public Petition PE 1031 (item 4)

Michael McMahon updated the group. As was mentioned at the last meeting, the Public Petitions Committee has received a petition from Professor Donald M Macdonald calling for Members of the Scottish Parliament to oppose the introduction of any legislation which would permit assisted suicide.

The Committee contacted the Scottish Partnership for Palliative Care to seek comments on the issues raised within the petition, and on the issues raised during the Public Petition Committee's discussion of the petition. The Partnership has drafted a response, and plans to consult its members over the next few months, before responding to the Committee in time for its next meeting in September.

Frank McAveety MSP has recently taken over from Michael McMahon as convenor the Public Petitions Committee.

5. Presentation and discussion:

Palliative and end of life care in Scotland: the case for a cohesive approach

Maria McGill, Chairman of the Scottish Partnership for Palliative Care and Chief Executive of Highland Hospice gave a presentation on the report and recommendations recently submitted by the Partnership to the Scottish Executive - *Palliative and end of life care in Scotland: the case for a cohesive approach*. (A copy of the presentation is attached as appendix 2)

The Scottish Partnership for Palliative Care identified a need to address inequities in palliative care provision by developing a cohesive approach to

palliative and end of life care in Scotland.

A short-life working group was accordingly set up to make recommendations to the Scottish Executive regarding the development of such a cohesive approach. Efforts were made to achieve a wide representation of interests on the group, and though the group did not include specific social work representation, social work colleagues were targeted at the consultation stage. Maria thanked members of the working group for their considerable hard work and commitment throughout the production of the report, and thanked all those who responded to the consultation.

The group debated the 'definition' of palliative and end of life care, recognising that the term 'end of life care' is used by different people to mean different things. The group agreed to entitle the report '*Palliative and end of life care: the case for a cohesive approach*' to reflect the fact that palliative care includes, but is not exclusively about, end of life care. The report focused on those elements of palliative care which are likely to be delivered in the last 12 months of life, including both general palliative care and specialist palliative care.

The remit of the group was to examine the tools for palliative and end of life care recommended in the Department of Health End of Life Care Programme:

- Gold Standards Framework (GSF)
- Liverpool Care Pathway for the Dying Patient (LCP)
- Preferred Place of Care (PPC) as an example of advanced care planning

and to consider these within the context of *Delivering for Health* and the wider Scottish health agenda. However, as the work developed, the group widened its scope to include consideration of other relevant developments which quickly came to its attention. These included:

- changes to out of hours service provision
- a possible approach to joint care management
- the Marie Curie Cancer Care Delivering Choice pilot project in Tayside
- the NHS Lothian 'Do not attempt resuscitation' (DNAR) framework and policy.

Between May 2006 and March 2007 the working group heard a number of presentations and examined a range of literature relating to each of these areas. The group also spent some time considering how these tools and initiatives related to recent policy developments which illustrate a growing recognition of the need to provide appropriate palliative care to all on the basis of need not diagnosis, and to provide patient-centred care, closer to home, with a shift from reactive, episodic care to continuous support. This included consideration of:

- *Our national health, a plan for action, a plan for change* (2000)
- *Cancer in Scotland: action for change* (2001)

- *Coronary heart disease and stroke strategy for Scotland (2002)*
- *Future care of older people in Scotland (2006)*
- *Joined up thinking...joined up care (2006)*
- *Making good care better; national practice statements for palliative care in adult care homes in Scotland (2006)*

After a full discussion and examination of information, the group undertook a consultation process involving the Partnership's members and other interested parties and agreed several recommendations. The recommendations centre on:

- supporting continued and expanding use of the principles and approach of the Gold Standards Framework Scotland in all care settings
- encouraging a uniform approach to achieving the goals of the Liverpool Integrated Care Pathway for the Dying Patient in all care settings, and
- clarifying some of the issues relating to out of hours service provision, DNAR policy, and joint working by health and social care.

Maria emphasised that the report and recommendations are intended to be a start, not the end, of discussions, and that the group was aware that it could not address all possible improvements to palliative and end of life care within a single report. However, the group is confident that these recommendations are achievable, and that they represent a cohesive set of changes which specifically move towards a cohesive approach and which can make a huge difference to patients and families.

The working group was clear that progress towards some of the outlined improvements could be made by re-design of services and reallocation of existing resources. However, full implementation of these recommendations would be reliant on the availability of additional resources, both to enable appropriate education and training, and in terms of dedicated support to facilitate the introduction and sustainability of improvements.

The report and recommendations are available on the website of the Scottish Partnership for Palliative Care: www.palliativecarescotland.org.uk

Michael McMahon opened this issue up to general discussion, and the following points were made:

- The Scottish Partnership for Palliative Care has taken over the GSFS database to ensure that the data collected by participating practices continues to be collated in a cohesive way.
- The report and recommendations were submitted in early May to Derek Feeley, Director of Healthcare Policy and Strategy at the Scottish Executive. Although there has been no formal commitment to a timescale, it is expected that a response will be received from the Scottish Executive within a few months.
- Free personal care, community care and palliative care are interconnected, since much of palliative care is provided by social care.
- The community nursing review was published in November 2006 (entitled:

Visible, Accessible and Integrated Care Report of The Review of Nursing in the Community In Scotland). Concerns were expressed that the vision set out within this document could be detrimental to palliative care provision, since it will mean changes to the ways in which GP's and DN's work together - with the current practice based model of community nursing changing to a community based model.

- It is important to ensure joint working at strategic and local levels, ensuring links with the care-management agenda and the long-term conditions strategy.
- England has a well-funded end of life care strategy. There is a need to consider whether Scotland would benefit from something similar, or whether strategy relating to palliative care could be combined with other related issues, for example chronic disease.

ACTION: The Partnership will consider getting in touch with the group responsible for implementing the findings of the Community Nursing Review, to assess ways of implementation that won't be detrimental to palliative care.

PW

6. Any other business

6.1 Future meetings

ACTION: Suggestions for agenda items for future meetings should be e-mailed to: Pauline@palliativecarescotland.org.uk

All members

7. Date of next meeting

The next meeting of the Cross-Party Group on Palliative Care will take place on Wednesday 5 December, at 5.45pm.