

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

Convener
Michael McMahon MSP

Vice Conveners
Roseanna Cunningham MSP
Jamie McGrigor MSP

Secretary
Patricia Wallace

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

**Wednesday 5 March 2008 at 5.45pm
Committee Room 3, Scottish Parliament Headquarters**

Present: Michael McMahon MSP (Convener) Bellshill & Hamilton
Roseanna Cunningham MSP, Perth
Jamie McGrigor MSP, Highlands and Islands
Dave Thompson MSP, Highlands and Islands

Philip Atkinson, Holyrood Magazine
Irene Barclay, St Columba's Hospice
Pauline Britton, Scottish Partnership for Palliative Care
Dr Duncan Brown, St Columba's Hospice
Sharon Burton, General Medical Council
Sandra Campbell, NHS Forth Valley
Jaqqi Carney, Highland Hospice
Dr Pat Carragher, Children's Hospice Association Scotland
Fiona Cathcart, St Columba's Hospice
Rev Stuart Coates, Strathcarron Hospice
Isobel Dosser, Napier University
Dr Cameron Fergus, NHS Borders
Roddy Ferguson, Audit Scotland
Shirley Fife, NHS Lothian
Liz Goss, Angus Community Health Partnership
Ann Gourlay, Perth & Kinross Community Health Partnership
Kerry Jackson, Children's Hospice Association Scotland
Bill Kerr, St Columba's Hospice
Linda Kerr, NHS Ayrshire & Arran
Elaine Maclean, Care Commission
Claire Murphy, St Margaret of Scotland Hospice
Dr David Oxenham, Marie Curie Hospice, Edinburgh
Dr Euan Paterson, RCGP Scotland
Rebecca Patterson, Scottish Partnership for Palliative Care
Andrew Powrie-Smith, British Lung Foundation, Scotland
Noreen Reid, Highland Hospice
Andrew Ritchie, Morhamburn Ltd
Anne Robb, NHS Tayside
Bob Shorter, NHS Lanarkshire
Dr Chris Sugden, St Andrew's Hospice
John Sweeney, Cancerbackup
Elizabeth Thomas, St Margaret of Scotland Hospice
Jane Todd, General Medical Council
Claire Walker, Cancerbackup
Patricia Wallace, Scottish Partnership for Palliative Care

Maggie White, Marie Curie Cancer Care
Anne Willis, Marie Curie Hospice, Edinburgh
Mary Wilson, Highland Hospice
Dan Wynn, General Medical Council

Apologies: Andrew Anderson, Maggie's Centres
Dr Paul Baughan, NHS Forth Valley
Dr Rosaleen Beattie
Jackie Bell, General Medical Council
Jo Bennett, SCAN
Dr TF Benton, St Columba's Hospice
Maureen Black, Macmillan Cancer Support
Susan Brimelow, Care Commission
Gill Chadwick, NHS Western Isles
Jacquelyn Chaplin, Prince & Princess of Wales Hospice
Dr Helen Charley, NHS Highland
Margaret Colquhoun, St Columba's Hospice
Margaret Dunbar, St Columba's Hospice
Joyce Dunlop, Roy Castle Lung Cancer Foundation
Ellen Finlayson, CLIC Sargent
Tom Gault, St Andrew's Hospice
Wilma Halley, NHS Highland
Dr Neil Houston, NHS Forth Valley
Professor Elizabeth Ireland, NHS Forth Valley
Kirsty Leavey, Strathcarron Hospice
Elaine MacNicol, BSN Medical
Dr Rosalyn Mauchline, St Vincent's Hospice
Dorothy McElroy, Ardgowan Hospice
Maria McGill, Highland Hospice
Irene McKie, Strathcarron Hospice
Susan Morrison, NHS Highland
Helen Newport, NHS Dumfries & Galloway
Dr Clive Preston, NHS Fife
Elaine Stevens, RCN Palliative Nursing Group
Craig Stockton, Scottish Motor Neurone Disease Association
Bill Stewart, Tak Tent Cancer Support Scotland
Professor John Welsh, NHS Greater Glasgow & Clyde
Dr Stanley Wright, NHS Forth Valley

1. Welcome and apologies

Michael McMahon MSP welcomed attendees to the meeting and introduced the three other MSPs in attendance: Dave Thompson MSP, Highlands and Islands; Roseanna Cunningham MSP, Perth; and Jamie McGrigor MSP, Highlands and Islands.

2 Minute of meeting of 5 December 2007

The minute of the most recent meeting of the group, held on Wednesday 5 December, was adopted as a true record. (Proposed: Rev Stuart Coates; Seconded: Dr Pat Carragher)

Action

3. Matters arising

3.1 Lymphoedema update (item 3.2)

The group previously heard that NHS Quality Improvement Scotland (QIS) plans to look at the British Lymphoedema Society document *Best practice for the management of lymphoedema* with a view to issuing recommendations regarding its adoption in Scotland. Michael McMahon updated the group that it had not been possible to get an update on progress with this due to a series of staff absences at QIS, but hopefully an update will be provided at the next meeting.

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

PB/PW

3.2 Palliative and end of life care in Scotland: the case for a cohesive approach (item 3.4)

Michael McMahon updated the group that the Scottish Government's *Better Health Better Care: Action Plan*, published in December 2007, confirmed the Government's commitment to the strategic development of palliative care services in Scotland and undertook to produce a plan by the end of March 2008 setting out how the Scottish Government will implement the recommendations contained within the Partnership's report '*Palliative and end of life care in Scotland: the case for a cohesive approach*'. Dr Elizabeth Ireland has recently been appointed National Clinical lead for palliative care on a part-time basis for 2 years to take this work forward.

3.3 The community nursing review:

Visible, Accessible and Integrated Care: Report of The Review of Nursing in the Community In Scotland (item 3.5)

Michael McMahon updated the group. Concerns had been expressed at a previous meeting about the possible effects of the community nursing review on palliative care in the community. The Scottish Partnership for Palliative Care consulted its members to gauge their views and wrote to the Programme Board outlining some of the concerns expressed by members about the implications the new model might have for palliative care, and expressing support for a developmental approach in taking this forward. In particular, the letter highlighted the important role that community nurses play in providing palliative care in the community, and emphasised the need for proper evaluation of the model before it is implemented. This letter has been acknowledged by the Programme Board. The Partnership is keeping itself and its members informed of developments by accessing and circulating community nursing review newsletters as they are published.

4 Presentation and discussion: 'You've got the wrong the disease': COPD and Palliative Care Services

Andrew Powrie-Smith, Head of the British Lung Foundation Scotland & Northern Ireland gave a presentation on chronic obstructive pulmonary disease (COPD) and palliative care services (slides attached).

The British Lung Foundation (BLF) works to provide information and

support to those diagnosed with lung disease. They also campaign for improvements in all areas of lung health, and invest money in research aiming to improve the diagnosis and treatment of lung conditions.

COPD is a disease state characterised by airflow limitation that is not fully reversible. The airflow limitation is usually both progressive and associated with an abnormal inflammatory response of the lungs to noxious particles or gases.

80% of COPD cases are associated with smoking, though occupational, environmental and genetic factors can also cause COPD. *Why* someone has COPD can affect their expectations – if people feel that it is their own fault that they have got COPD they are likely to have lower expectations of the care they should receive. People with COPD generally have low expectations of what they can expect from healthcare services, and the BLF would argue that healthcare workers need to therefore have high expectations on behalf of their patients.

COPD is the only major cause of death that has been increasing in recent years, and Scotland has one of the highest rates of COPD in Europe. COPD is the fourth most common cause of death in Scotland, and primary care data suggests that over 90,000 people live with COPD in Scotland, with approximately 4500 people dying with the condition each year. COPD is most likely to affect people over 60, and many people with COPD don't seek medical attention until quite late on in the progression of the disease. Though people from all backgrounds suffer from COPD, it is most likely to affect those in the most deprived "deprivation category", and this is not solely attributable to known factors such as smoking.

The BLF has for a long time seen COPD as an area that has not attracted the attention it deserves, though the political context is now changing. The Scottish Government has recently committed to providing funding in support of new and existing Managed Clinical Networks for respiratory conditions. Clinical standards are going to be developed and there is increasing recognition of the needs of patients. There is also a general acceptance that improvements need to be made in the area of palliative care for those with conditions other than cancer.

45-75% of people with COPD suffer from isolation and depression. COPD makes it difficult for people to get out of the house, and though in other countries portable oxygen cylinders are available which last for eight hours, in the UK the only portable oxygen available lasts for just two hours.

Another of the real burdens of COPD is fear and anxiety, caused by breathlessness. Fear and anxiety make breathlessness worse, causing people to stay inside and become less fit, which also makes the breathlessness worse which makes the fear and anxiety worse, turning this into a vicious cycle.

COPD patients have many palliative care needs, and figures indicate that in fact COPD patients have a greater symptom burden than those with lung cancer, yet are less able to access palliative care services. Palliative care

for respiratory patients is seen as being difficult because the terminal phase is difficult to define, patients have low expectations, there are many near death episodes, and because palliative care has historically been seen as being for cancer patients only, and then only for the dying. In addition, patients with chronic lung disease often don't know that they are dying.

Patients with COPD do not want to hear that it is "too difficult" to give them palliative care, or that palliative care services might "get swamped". Nor do they want to hear that "their journey is wrong" meaning they can't access palliative care. There is therefore an urgent need to re-organise services and make plans to meet the needs of this growing group of patients.

General questions and discussion followed, and the following points were raised:

- This presentation highlighted many of the current difficulties in providing palliative care to this group of patients, and it is important to look for the answers to these problems. The BLF believes that people with COPD want to be at home rather than in hospital, which is currently the default option. The BLF therefore sees the answers as being:
 - prevention
 - early supported discharge
 - community based, nurse-led support at home, with continuity of care provided by giving existing nurses palliative care training.
- The issue of resources was raised, since providing care to help people die at home can be extremely resource intensive, and it could be argued that there simply aren't enough resources to provide this level of care for everyone who requires it. The BLF would say that COPD patients have been disadvantaged for a long time in terms of resources, and that solutions can be found, such as work by the Scottish Primary Care Collaborative looking at the Gold Standards Framework Scotland (GSFS) in this context.
- Most COPD patients have been admitted to hospital many times and are very knowledgeable about the procedures that they will undergo. They are therefore in a good position to be able to self-manage their condition, and resources and education are required to provide good generic District Nurses to support these patients to self-manage their condition at home.
- The Marie-Curie Delivering Choice Project in Tayside is looking at when patients with non-malignant conditions access palliative care, and have set up a day care environment which has been used a lot by COPD patients.

5. Discussion: GMC Review of the 2002 publication '*Withholding and Withdrawing Life-prolonging Treatments: Good Practice in Decision-making*'

At the December meeting, the group was informed that the General Medical Council (GMC) is reviewing its publication *Withholding and Withdrawing Life-prolonging Treatments: Good Practice in Decision-making* which was published in 2002. A background paper explaining why a review of the guidance was necessary was tabled (attached) and Sharon Burton, Senior Policy Advisor at the GMC provided more information about how the GMC

might contribute to improved practice in palliative and end of life care through:

- ensuring that GMC guidance covers the key areas that clinicians and patients have identified as essential to good care
- providing advice that carries the authority of the regulator on issues which are seen as ethically and/or legally contentious, such as CPR and artificial nutrition and hydration
- feeding into medical education and training for established doctors as well as people entering the medical profession.

In 2006 the GMC ran workshops looking at the impact the current guidance has had on standards of palliative and end of life care. It emerged that there was still a need for clinicians to gain confidence in ethics and legislation around end of life decision making. Also, that this understanding needs to be fed into broader messages such as partnership working, and that consent and decision-making guidance needs to have patient interests at its centre.

The GMC has recently set up a working group to look at updating the guidance, and is drawing on expertise from clinical communities and patients. The first meeting of this working group took place on 22 February 2008, and meetings are likely to run until the end of 2008 when new guidance will be circulated for consultation.

The GMC is looking for ways to reach communities to ensure that it is aware of dimensions that should either be included in this guidance, or reflected in other ways, for example education and training. It is hoped that the new guidance will address issues such as where people want to spend the last days of life and how to manage the relationship with the family. The new guidelines are a chance to expand awareness of what makes good palliative and end of life care.

The GMC is looking at expanding its role in future to include regulation and providing materials to support best practice. These materials should give clarity to patients and carers as to what good practice should look like, in a clear constructive and helpful way. They hope to go on to work with clinicians and care associations to ensure this guidance is picked up in practice.

General questions and discussion followed. Interest was expressed in how GMC guidance on good practice feeds into set requirements for the undergraduate medical curriculum, postgraduate Foundation training programmes, and how it will in the future influence the content of CPD programmes through interconnection between local appraisal systems and the requirements the GMC sets for revalidation.

The issue of partnership working and resources was raised, and connected to the perceived growth of “super-specialism”. It was argued that the time invested into partnership decision-making should pay off in less demand “down-stream”, and that raising issues during early training should help build up knowledge base so it becomes an integral part of decision-making throughout a doctor’s career.

The issue of autonomy and decision-making was also raised, and it could be argued that patients now expect too much choice and autonomy. This creates the need for debates about whether people should be educated in what they can reasonably expect. As a regulator, the GMC are trying to reach common ground about what is both reasonable to expect and practical to deliver.

Attached as appendices 1 and 2 respectively are a summary of relevant case law since 2002 and a presentation explaining the GMC's role in education and training and how current curriculum framework documents cover end of life care issues.

6. Any other business

6.1 Modernising Medical Careers (MMC)

The CPG had previously agreed to drop this item from its agenda. However, since the last meeting, Professor Sir John Tooke has published his report on MMC: *Aspiring to Excellence* (8 January 2008). His report suggests a reworking of many aspects of postgraduate medical education (PGME) and contains detailed recommendations (full details available at www.mmcinquiry.org.uk). The Scottish Government has produced a consultation paper concentrating on the relevant actions being taken in Scotland, and inviting members of the public for their views.

The Scottish Partnership for Palliative Care is currently seeking the views of nominated member representatives regarding submission of a Partnership response to this Scottish Government consultation and will update the CPG again at the next meeting.

ACTION: Agenda item next meeting

PB/PW

7. Future meetings

The next meeting of the Cross Party Group on Palliative Care will take place on Wednesday 11 June 2008, at 5.45pm, and will include the group's annual general meeting (AGM).

An additional meeting of the group will also be arranged to take place jointly with the Cross Party Group on International Development. Further details of this meeting will be provided at a later date.

ACTION: The Partnership to take forward

PB/PW