

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

Convener
Michael McMahon MSP

Vice-Conveners
Jamie McGrigor MSP
Dennis Robertson MSP

Secretary
Mark Hazelwood

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

**Wednesday 13 March 2013 at 5.45pm
Committee Room 1, Scottish Parliament**

Present:

Michael McMahon MSP (Convener)
Siobahn McMahon MSP

Jackie Bell, GMC Scotland

Alison Blezard, Scottish Kidney Federation

David Brown

Marjory Burns, British Heart Foundation, Scotland

Sandra Campbell, NHS Forth Valley

Christine Carlin, MS Society

Rev Stuart Coates, Association of Hospice and Palliative Care Chaplains

Margaret Colquhoun, St Columba's hospice

Jan Dobie, NHS Lothian

Dr Derek Doyle, Scottish Partnership for Palliative Care

Dr Rosalie Dunn, NHS Lanarkshire

Shirley Fife, NHS Lothian

Pauline Gibb, St Columba's Hospice

Eleanor Grant, NHS Lanarkshire

Moira Hamilton

Mark Hazelwood, Scottish Partnership for Palliative Care

Vicky Hill, St Columba's Hospice

Evelyn Howie, St Columba's Hospice

Dr Elizabeth Ireland, Scottish Government/HIS

Gillian Ireland

Craig Jackson

Linda Kerr, NHS Ayrshire and Arran

Kate Lennon, St Vincent's hospice

Christine Lilley, NHS Lothian

Dr Sandra McConnell, NHS Greater Glasgow and Clyde

Irene McKie, Strathcarron Hospice

June Anne McKnight

Gordon McLaren, NHS Fife

Elaine MacLean, Care Inspectorate

Jane Miller, Prince and Princess of Wales Hospice

Libby Milton, Prince and Princess of Wales Hospice

Clare Murphy, St Margaret of Scotland Hospice

Roslyn Neely, CHAS

Rebecca Patterson, Scottish Partnership for Palliative Care

Sinead Power, Scottish Government

Anne Robb, NHS Tayside

Mrs Ann Scott

Tracey Smith, NHS Lothian

Dr Juliet Spiller, MCCC
Helen Stevens, Scottish Government
Craig Stockton, MND Scotland
Joyce Stuart
Elizabeth Thomas, St Margaret of Scotland Hospice
Susan Webster, MND Scotland

Apologies

Jackie Baillie MSP
Jamie McGrigor MSP

Patricia Brooks-Young, NHS Lothian
Dr Pat Carragher, CHAS
Eileen Cowey, University of Glasgow
Ellen Finlayson, CLIC Sargent Cancer Care for Children
Gail Grant, BMA Scotland
Dr Peter Kiehlmann, NHS Grampian
Dr Sally Lawton, NHS Grampian
Karen Nolan, NHS Fife
Ros Scott, CHAS
Helen Simpson, ACCORD Hospice
Elaine Stevens, IANPC

1. Welcome, introductions & apologies

Michael McMahon welcomed everyone to the meeting and noted that a list of apologies would be included in the minute.

2. Minute of previous meeting (12 December 2012)

The minutes of the meeting of 12 December were approved. (Proposed: Stuart Coates; Seconded: Susan Webster.)

3. Matters arising from the meeting of 12 September 2012

3.1 Margo MacDonald MSP's Proposed Assisted Suicide Bill (3.1)

Michael McMahon updated the group that Assisted Suicide Bill proposed by Margo Macdonald MSP is awaiting time being allocated in the parliamentary timetable for its debate.

4 Presentation and Discussion: Caring for people who are dying; reflections on the Liverpool Care Pathway.

Dr Rosalie Dunn, Macmillan GP Facilitator in NHS Lanarkshire gave a presentation, reflecting on the LCP from a doctor's perspective. This was followed by a presentation by David Brown, who contrasted his distressing experiences of his mother dying alone and without the LCP, with his more positive experiences of his father dying in an environment where the LCP was used. (Presentations attached.) Eleanor Grant, Macmillan Nurse at NHS Lanarkshire was present to bring a nursing perspective to discussions.

There was then opportunity for questions and discussion, and the following issues were raised:

- Michael McMahon shared his personal experience of high levels of care and compassion as his mother died a care home where the LCP was used.
- Two sisters in the group shared their experiences of their father dying on the LCP in hospital, and their extreme distress watching their father take eleven days to die. Thought they had been involved in the decision to use the LCP, they felt that there had been poor communication and support from staff, and that families need to be helped to understand

what is happening, what to expect and that staff need to be clear that the LCP is not just a 'tick box' exercise.

- The sisters shared their concern that their father's death certificate had been completed inaccurately as attributing cause of death to 'dementia'. A new system of death certification is currently being introduced which should improve the accuracy of death certificates.
- Nurses feel care and compassion for the patients and families they work with, but often just don't have the time to give all the support they would wish.
- A scheme is being piloted in Wishaw whereby volunteers make themselves available to sit with families, and staff are given the chance to reflect after every death.
- Dying can be distressing and difficult – it is not the LCP that causes this – it is just the often unavoidable nature of dying.
- The media has presented to people that the LCP makes people die, and therefore people feel guilty for having agreed for their loved one put on the LCP. However, the LCP doesn't create the situation – it doesn't make people die. Without it, people would be dying, but their relatives would be less likely to know about it.
- Is it possible to get confidence back in the LCP? If not, how can the spirit of the pathway be maintained? Is 'end of life priorities' a useful phrase?
- How can we maintain the benefits of the pathway without making it a 'tick box' approach?
- Part of the challenge is *when* someone goes on the pathway. Many people die without the LCP being used, because staff don't want to use the pathway too early, and this results in no chance for relatives to say goodbye.
- Maybe we need to ask for more support for the LCP and for those using it.
- It is completely inappropriate that the LCP be discussed alongside euthanasia.
- Many tools and pathways are used within healthcare, but in general it isn't seen as necessary that practitioners share the details of these with patients and families. Why is the LCP different? Why not just talk to people honestly?
- Education and communication are key to improving people's experiences relating to dying in hospitals:
 - o The LCP needs to be supported by excellent communication
 - o It is important that education about the LCP gets to the staff who need it.
 - o People are uncomfortable with a range of issues relating to death, dying and bereavement, and a lack of understanding and openness makes distressing experiences worse. This is why the alliance *Good Life, Good Death, Good Grief* has been set up.
 - o The problem isn't with the LCP – it is about giving relatives an opportunity to discuss the issues that are concerning and distressing them.
 - o There is a need for healthcare staff to be educated in the process of dying and having conversations about death.
 - o This education/openness needs to be extended more widely, for example to social care and mainstream education, including helping children to grow up learning about these issues.

A copy of the presentations is attached as Appendix A.

5 Any other competent business

No further business was discussed.

6 Dates of future meetings

- Wednesday 12 June 2013 (includes AGM) – Committee Room 3
- Wednesday 11 September 2013 – Committee Room 3
- Wednesday 11 December – Committee Room 3