

**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

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

**Wednesday 20 June 2012 at 5.45pm
Committee Room 4, Scottish Parliament**

Present:	Michael McMahon MSP Siobhan McMahon MSP Phil Atkinson Matt Barclay Jackie Bell Patricia Black Alison Blezard Aileen Bryson Rev Stuart Coates Carol Graham Peter Hastie Irene McKie Dr Gordon McLaren Karen Nolan Naomi Phillips Elaine Stevens Elizabeth Thomas	Member for Uddingston and Bellshill Member for Central Scotland Health Policy Scotland Journalist Community Pharmacy Scotland General Medical Council NHS Lothian Scottish Kidney Federation Royal Pharmaceutical Society Association of Palliative Care Chaplains Prince & Princess of Wales Hospice Macmillan Cancer Support Strathcarron Hospice NHS Fife NHS Fife General Pharmaceutical Council IANPC St Margaret of Scotland Hospice
In attendance:	Joy Elliot Mark Hazelwood Bruce Nicol Imelda Redmond Derek Blues	Accord Hospice Scottish Partnership for Palliative Care Marie Curie Cancer Care Marie Curie Cancer Care Scottish Partnership for Palliative Care
Apologies:	Jackie Baillie MSP Jamie McGrigor MSP Dennis Robertson MSP Richard Simpson MSP Dave Thompson MSP John Bannon MBE Dr Duncan Brown Sandra Campbell Margaret Colquhoun Helen Dryden Shirley Fife Ellen Finlayson Sally Lawton Pamela Mackenzie Elaine MacLean Maria McGill	Member for Dumbarton Member for Highlands and Islands Member for Aberdeenshire West Member for Mid Scotland and Fife Member for Skye, Lochaber and Badenoch Health Watch Scotland St Columba's Hospice NHS Forth Valley St Columba's Hospice NHS Tayside NHS Lothian CLIC Sargent NHS Grampian Sue Ryder Cancer Care Care Inspectorate CHAS

**Apologies:
(continued)**

Dr Sandra McConnell
 Professor Scott Murray MBE
 Euan Paterson
 Anne Robb
 Geoff Sage
 Helen Simpson
 Ewan Maclean
 Maggie White
 Kenny Steele

Ardgowan Hospice
 University of Edinburgh
 RCGP (Scotland)
 NHS Tayside
 St Andrew's Hospice, Airdrie
 ACCORD Hospice
 Scottish Kidney Federation
 Marie Curie Cancer Care
 Highland Hospice

Action**1. Welcome, introductions & apologies:**

Michael McMahon welcomed the cross party group members to the meeting and noted apologies for a change in circumstances which had meant that a number of MSPs who had been intending to come along to the meeting were not now able to attend.

2. Annual General Meeting 2012

In the absence of other MSP members, Michael McMahon advised that the AGM would proceed but subsequent ratification of the various approvals would be obtained.

Members present were in agreement with this approach.

**MM to
obtain
MSP
ratification**

2.1 Minute of AGM of 29 June 2011

The minute of the AGM of 29 June 2012 was tabled and considered for approval. There were no amendments and the minute was agreed.

Proposed by: Rev Stuart Coates

Seconded by: Irene McKie

2.2 Annual return and accounts 2011-12

The annual return was tabled and considered for approval. There were no amendments and the return was approved.

Proposed by: Dr Gordon McLaren

Seconded by: Rev Stuart Coates

The unapproved accounts were tabled and considered for approval. There were no amendments and the accounts were approved.

Proposed by: Rev Stuart Coates

Seconded by: Dr Gordon McLaren

2.3 Annual Subscription

Michael McMahon noted that this particular cross party group operated without the need for a subscription and proposed that this continue for 2012-2013. Members present agreed with the proposal.

2.4 Election of Office Bearers - Convenor

Michael McMahon passed the meeting to Mark Hazelwood to lead on the election of office bearers. Mark noted that Michael McMahon had intimated a willingness to continue as Convenor of the cross party group.

Members present re-elected Michael without opposition or hesitation.

Proposed by: Rev Stuart Coates

Seconded by: Irene McKie

Election of Office Bearers – Vice Convenors

Michael McMahon thanked members present and noted that Jamie McGrigor MSP and Dennis Robertson MSP had intimated a willingness to continue as Vice-Convenors of the cross party group.

Members present re-elected both Vice-Convenors without opposition or hesitation.

Proposed by: Rev Stuart Coates

Seconded by: Dr Gordon McLaren

Election of Office Bearers – Secretary/Treasurer

Mark Hazelwood was re-elected as Secretary and Treasurer of the Cross Party group.

Proposed by: Rev Stuart Coates

Seconded by: Irene McKie

The AGM closed at 18:15

3. Minute of previous meeting of Wednesday 21 March 2012

The minute of the meeting held on Wednesday 21 March 2012 was approved without amendment.

4. Matters arising from the previous meeting of 21 March 2012

There were no matters arising from the meeting of 21 March 2012 not already covered on the agenda.

5. Presentation and discussion: *Carers, palliative care & end of life care*

Michael McMahon welcomed Imelda Redmond and Bruce Elliot from Marie Curie and Joy Elliot from Accord Hospice.

Imelda Redmond (Policy & Public Affairs Director, Marie Curie) noted that she was particularly pleased to be asked to participate in the session given her previous role as Chief Executive of Carers UK. Marie Curie was participating in a large number of local and national events designed to recognise the important role of unpaid carers in the provision of palliative and end of life care.

Imelda also noted the theme of carers week as “In Sickness and In Health” highlighting that as carers often don’t see themselves as a carer there can often be a significant impact in the health of a carer resulting in emergency hospital admission for the carer or the person they are caring for.

Marie Curie are committed to understanding the family dynamics in all of their cases to try and ensure that the care and support they are providing helps to ensure dignity in all types of care. She also noted a 50% increase in the number of people providing 50 or more hours of care each week. The changing demographic in the country was leading to a situation where more support at home in the future would be needed.

Bruce Nicol (Policy & Public Affairs Manager (Scotland), Marie Curie) highlighted the publication of the report *Committed to Scotland Carers* which reported on the effects of caring for the terminally ill from the carers perspective. Key recommendations from the report were noted as follows:

- Carers for those at the end of life need support in order to be able to identify themselves as carers.

- Health and Social care professionals should ensure carers are included in conversations about their loved one's condition.
- As patients are placed on a palliative care register, the carer should automatically be offered a carers assessment.
- The need for respite breaks and admission to hospital should be properly considered by healthcare professionals
- Carers need clear and easily accessible information about support and benefits.

Both Imelda and Bruce noted for the meeting that whilst this was being discussed in Carers week, the work was something that should happen at all times, not just in a week focussed on carers.

Joy Elliot addressed members present and explained that although she worked at Accord Hospice, she was at the meeting to share her experience as a daughter/ carer having spent a significant amount of time caring for her mother who had died on 18 August 2011. In a very powerful presentation Joy, went on to tell the story of her experiences, feelings, emotions and demands in the final weeks of her mother's life. The key points noted in the presentation were as follows;

Joy's mother had previously expressed a wish to die at home and Joy reflected that whilst she had undertaken to support this wish, the reality of delivering this was not possible and that the learning point was that promises made can often be difficult to deliver.

On admission to an acute hospital September 2011, Joy felt that communication was very poor. When her mum had been admitted, she was left sitting waiting for news for a long period and was then taken through to find her Mum in resuscitation and very unwell.

After some helpful and on-going support from a heart failure nurse, and continued family support, a package of care was arranged. On the face of it, this seemed like a god-send however the reality was that a number of relatively untrained and unskilled carers were introduced and often had only 10-15 minutes 3 times a day to provide support which seemed to be delivered in a fairly inflexible manner. It was also difficult to access services as there had been no formal documentation of dementia which would have given access to the appropriate day-care services.

After another heavy fall in June 2012, Joy made the decision not to have her Mum admitted to hospital as it was a Saturday night and previous experiences of her Mum being there for many hours in A&E only added to her Mum's confusion. This was the onset a huge deterioration which also was during a particularly stressful time for the family with other major events all happening at the same time. One bright moment was when Joy's grandchild was born and the family had a lovely photograph taken with Joy's mum and her first great grand-child.

Care at home proved increasingly difficult with very little support available and daily demands increasing, leading to an increasing carers burden resulting in a need to move in as a 24/7 carer. Joy described this as the biggest challenge of her life.

As time moved on, admission to a hospice became possible and although this was initially thought of as a failure, Joy's mum seemed quite content with that as an option.

This presented personal challenges as it meant Joy being in her place of work but in a very different role.

Joy had made journals and taken lots of photos of her mum in the last weeks of life and was pleased that at the end of life, her mum had a dignified and pain free death but felt that as a country there was more that we could do to create services that would enable people to stay at home for as long as possible.

At the conclusion of her story, Joy was kind enough to share the photograph that had been taken with her mum and her grand-daughter.

Members thanked Joy for her presentation with a round of applause and Michael McMahon made a personal thank you to Joy reflecting on his own experiences over recent months.

Members present had a lengthy discussion about the experience that Joy had had as a carer and noted the following:

- Continuity of care seems to be an ever increasing challenge with a large number of different unpaid carers being involved in individual cases. This can be particularly distressing for patients with cognitive impairment.
- Often the role of the paid carer is very difficult as they are being paid on a very low wage and feel they have limited time with each patient before being asked to then move on to the next person. There is also a lack of training when the needs of the patient are changing particularly nearing the end of life
- A carers assessment had clearly not been undertaken in this case and that might have helped highlight some of the issues before they became overly problematic.
- Carers services seem to operate around a 9 to 5 service whereas around 80% of unpaid carers are of working age so it would seem that often the services that are available, don't necessarily meet the needs of the carer.
- The challenges for carers in understanding the medications involved seems to be a big factor, often under-estimated by the prescribers.
- Care in this case seemed to be anything other than person-centred and members reflected on this challenge in considering the current health and social care integration agenda.
- The preferred place of care (and death) may often change as circumstances change. This should not be seen as a failure in care, it is a reality of how care is best provided.

In a closing reflection, Joy noted her thinking as she was going through this experience and summarised it as "That will be me some day, I wonder what it will be like then?"

On behalf of the group the Convener thanked Imelda and Bruce and particularly Joy Elliot for their presentations and members for participating in an excellent discussion.

6. Any other competent business:

6.1 Margo MacDonald MSP's Proposed Assisted Suicide Bill

Mark Hazelwood noted that there had been no progress with the Bill and that an update would be provided at a later meeting.

6.2 SPPC Annual Conference and AGM 2012

Mark Hazelwood noted the date of the SPPC conference as Thursday 11 October 2012 and that the programme and details of that discounted booking rates for members and groups were available through the SPPC website at: http://www.palliativecarescotland.org.uk/content/annual_conference_2012/

7. Date of future meetings:

- 12 September 2012, Committee Room 4
- 12 December 2012, Committee Room 4

On behalf of members of the Cross Party Group, Mark Hazelwood thanked Michael McMahon for chairing the meeting.

There being no further business the meeting closed at 19:15