

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

Convener
Bob Doris MSP

Vice-Conveners
Miles Briggs MSP
Emma Harper MSP
Colin Smyth MSP

Secretary
Mark Hazelwood

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

**Wednesday 5 September 2018 at 5.45pm
Committee Room 4, Scottish Parliament**

Present: Bob Doris MSP
Emma Harper MSP
Colin Smyth MSP

Gail Allan, Macmillan Project Lead for Palliative Care and End of Life Care in Prisons

Iain Armstrong, British Heart Foundation Scotland

Paul Baughan, NHS Forth Valley/ HIS

Louise Burns, NHS Forth Valley

Sandra Campbell, NHS Forth Valley/ HIS

Suzanne Cameron-Nielson, CHAS

Emma Carduff, Marie Curie Hospice, Glasgow

Mark Chapman, DMD Pathfinders

Lara Celini, Humanist Celebrant

Rebecca Chaddock, St Columba's Hospice

Rev Margery Collin, Strathcarron Hospice

Heather Edwards, Care Inspectorate

Trish Elder-Gracie, NHS Lothian

Pauline Ellison, Scottish Partnership for Palliative Care

Becky Everett, Leuchie House

Fiona Finlay, NHS Greater Glasgow and Clyde

Geraldine Finnan, NHS Borders

Anne Finucane, Marie Curie Hospice Edinburgh

Liz Forbat, University of Stirling

Sheri Mila Gerson, University of Glasgow, Dumfries Campus

Mark Hazelwood, Scottish Partnership for Palliative Care

Annabel Howell, NHS Borders

Elinor Jayne, Sue Ryder

Anne Kelly, NHS Tayside

Fiona Kerr, NHS Greater Glasgow and Clyde

Marian Krawczyk, University of Glasgow

Eilidh Macdonald, Hospice UK

Laura Mackintosh, NHS Forth Valley

Sharon McCaffrey, Prince and Princess of Wales Hospice

Maria McGill, CHAS

Marjory McKay, Strathcarron Hospice

Irene McKie, Strathcarron Hospice

Present: Richard Meade, Marie Curie

Cross-Party Group in the Scottish Parliament on Palliative Care

Secretariat: Scottish Partnership for Palliative Care

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(cont.) Tanith Muller, Parkinson's UK
John Miller, Action Duchenne
Maureen O'Neill, Faith in Older People
Euan Paterson, RCGP
Rebecca Patterson, Scottish Partnership for Palliative Care
Andrew Reeves, Marie Curie
Diane Rennie, NHS Lothian
Keith Robertson, Cruse Bereavement Care Scotland
Keith Robson, MS Society Scotland
Kirsty Lynn Smith, Macmillan Cancer Support
Michelle Scott, NHS Borders
Ros Scott, Volunteering Researcher and Consultant
Gillian Sherwood, Prince and Princess of Wales Hospice
Lorna Stewart, NHS Fife
Ruth Yates, NHS Greater Glasgow and Clyde

Apologies: Miles Briggs MSP
John Birrell, Bereavement Consultant
Duncan Brown, St Columba's Hospice
Josaleen Connolly, NHS Ayrshire and Arran
Marina Copping, NHS Lothian
Jean Davies, Crosshouse Hospital
Derek Doyle, SPPC
Joy Elliot, ABSCo
Cornelia Featherstone MRCGP, Retired GP
Trisha Hatt, Macmillan Cancer Support
Sheonad Laidlaw, NHS Greater Glasgow and Clyde
Susan Lowes, Marie Curie
David McArthur NHS Orkney
Collette McDiarmid, MND Scotland
Linda McEnhill, Ardgowan Hospice
Sally Mercer, University of Strathclyde
Iona Philp, NHS Tayside
Kenny Steele, Highland Hospice
Elaine Stevens, International Association of Nurses in Palliative Care
Julie Watson, University of Edinburgh
Susan Webster, MND Scotland

1. Welcome, introductions and apologies

Convenor of the group Bob Doris MSP welcomed everyone to the meeting. Introductions were made and apologies noted.

2. Annual General Meeting 2018:

2.1 Minute of AGM 6 September 2017 (paper 2)

The minute was approved as an accurate record of the meeting.

2.2 Annual Return and Accounts 2016-2017 (papers 3a & 3b)

The Convenor noted the 'in kind' contribution of the SPPC to the running of the group. The Annual Return and Accounts 2016-2017 were unanimously approved.

2.3 Annual Subscription 2017-2018

The Convenor noted that the Cross-Party Group currently operated without

Action:

the need for a subscription and proposed that this continue for the following year.

Members present agreed with that proposal.

2.4 Election of Office Bearers

Bob Doris passed the Chair to Mark Hazelwood to lead on the election of office bearers.

2.4.1 Election of Convenor: Mark noted that Bob Doris had indicated a willingness to continue as Convenor. Bob Doris was re-elected as Convenor.

(Nominated by Emma Harper, Seconded by Colin Smyth.)

2.4.2 Election of Vice-Convenors: Bob Doris re-assumed the role of Chair and noted that Colin Smyth MSP and Miles Briggs MSP were willing to continue as Vice-Convenors of the cross-party group. Emma Harper MSP was willing to join the group as Vice-Convenor. All three were elected as Vice-Convenors.

(Emma Harper nominated by Bob Doris, seconded by Colin Smyth; Colin Smyth nominated by Bob Doris, seconded by Emma Harper; Miles Briggs nominated by Colin Smyth, seconded by Emma Harper.)

2.4.3 Election of Secretary/Treasurer: Mark Hazelwood was re-elected as Secretary and Treasurer of the Cross-Party Group.

3. Approval of minute of previous meeting of Wednesday 6 June

The most recent two cross party group meetings weren't quorate, as there was only one MSP present. This means that they can't be counted as 'official' cross party group meetings. The notes of these meetings have been circulated to the group and will be made available on the Scottish Partnership for Palliative Care website as a record of useful (if 'unofficial') meetings.

4. Matters arising from Tuesday 6 March 2018

4.1 Palliative care in acute hospitals

Bob Doris followed up discussions at the December 2017 meeting with a letter to Shona Robison about the importance of a strategic approach to palliative and end of life care in hospitals.

ACTION: Bob Doris to chase up a reply to this letter

BD

5. Presentations and Discussion: Human Rights and Palliative Care

Presentation: Human Rights, Personhood and Palliative/ End of Life Care given by Donald Macaskill, Chief Executive, Scottish Care.

Presentation: 'What matters to me': Sue Ryder's human rights approach to end-of-life care given by Jude Scott, Practice Educator, Sue Ryder.

Discussion

The speakers' PowerPoint slides will be circulated with the minute.

Presentations were followed by opportunities for group discussion, which included the following issues:

- The relationship between human rights and resource allocation – some would say that if you can't live life to the fullest because someone else has mis-allocated resources, it is a human rights issue.
- The rights of a family to be involved in/aware of Do Not Attempt CPR decisions.
- Balancing the potentially conflicting human rights needs of different

individuals.

- The potential for communications and understanding to reduce conflict.
- The gap between human rights policies and how they are put into practice.
- Mis-use and misunderstanding of the concept of 'human rights' and its potential to lead to negative perceptions of human rights.
- The need for a framework to help policy makers make decisions about resource allocations that take into account human rights.
- Complications that can arise when people disagree with each other about what is in the best interests of a child.
- The need to increase the public's understanding of human rights, and the role that the Curriculum for Excellence is already playing in this.
- The need to enable patients to take risks if they wish to.
- The potential impact of making human rights a political priority, and of embedding human rights into macro budget decision-making.
- The need to encourage MSPs and everyone who makes decisions in the public sector to go through human rights training.

ACTIONS:

- **SPPC will share Jude Scott's contact details** **SPPC**
- **SPPC will circulate a link to Scottish Care's report: [Tech Rights: Human Rights, Technology and Social Care](#)** **SPPC**
- **SPPC will look into what other Cross-Party Groups exist that are already working on human rights, and if there is anything that this Cross-Party Group can do to support that work. (For example, the ACEs Cross Party Group may have an interest in the rights of children.)** **SPPC**
- **Bob Doris will write to the Scottish Parliament Health Committee to ask them to give consideration to Human Rights and what can be done to raise awareness of them.** **BD**
- **Bob Doris will find out more information about Human Rights training for parliament staff.** **BD**

6. Any other competent business

6.1 SPPC Annual Conference

Mark Hazelwood reminded the group that the Scottish Partnership for Palliative Care Annual Conference will take place on the 28th November and would feature a session on human rights.

7. Dates of next meeting

- Wednesday 12 December 2018; The Fleming Room TG.60-CR3; 5.45pm to 7.30 pm