

**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

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

**Wednesday 12 December 2018 at 5.45pm
Committee Room 3, Scottish Parliament**

Present:	Bob Doris MSP (Chairman) Mark McDonald MSP	Member of the Scottish Parliament for Glasgow Maryhill and Springburn Member of the Scottish Parliament for Aberdeen Donside
	Pat Carragher Heather Edwards Pauline Ellison Jayne Grant Mark Hazelwood Fiona Herd Sue Hogg Donald MacAskill Cari Malcolm Linda McEnhill Julie McGill Maria McGill Debbie McGirr Rami Okasha Rebecca Patterson Christine Thompson Tim Warren Mandy Yule	CHAS Care Inspectorate Scottish Partnership for Palliative Care CHAS Scottish Partnership for Palliative Care The Newcastle Upon Tyne Hospitals NHS Foundation Trust CHAS Scottish Care Edinburgh Napier University Ardgowan Hospice NHS Lothian CHAS Edinburgh Napier University CHAS Scottish Partnership for Palliative Care NHS Lothian Scottish Government Ayrshire Hospice
Apologies:	Iain Armstrong Paul Baughan Duncan Brown Sandra Campbell Lara Celini Rev Margery Collin Sally Egan Harriet Hay Annabel Howell Rachel McAndrew David McArthur Sandra McConnell Irene McKie Stuart Milligan Juliet O'Donnell Maureen O'Neill Euan Paterson Ros Scott Kenny Steele	British Heart Foundation Scotland NHS Forth Valley/ HIS St Columba's Hospice NHS Forth Valley/ HIS Humanist Society Scotland Strathcarron Hospice NHS Lothian ABSCo NHS Borders NHS Lothian NHS Orkney Ardgowan Hospice Strathcarron Hospice Ardgowan Hospice St Columba's Hospice Faith in Older People GP Volunteering Researcher and Consultant Highland Hospice

1. Welcome, introductions and apologies

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

2. Matters arising from Wednesday 5 September 2018**2.1 Palliative care in acute hospitals**

Following the December 2017 meeting of the group, Bob Doris wrote to the Cabinet Secretary (Shona Robison MSP) raising the subject of palliative care in hospital settings. No reply to this letter has yet been received. Tim Warren (Scottish Government) apologised for this oversight and will do what he can to ensure the group receives a reply before the next meeting. Tim updated the group on the most recent meeting of the National Implementation Advisory Group (NIAG) and assured the group that palliative care in hospitals will be considered by the NIAG.

2.2 Human Rights

Human Rights was the focus of discussion at the September meeting. Since that meeting Bob Doris has written a letter to the Scottish Parliament Health Committee asking them to consider a human rights-based approach to resource allocation. He has investigated what training is available to MSPs relating to Human Rights, and found that though currently nothing specific is available, any MSP can put in a request for a course.

Donald MacAskill updated the group that since the last meeting, the Scottish Parliament Equalities and Human Rights Committee has launched a report [Getting Rights Right: Human Rights and the Scottish Parliament](#).

The report outlines 40 recommendations aimed at bolstering the Scottish Parliament and MSPs' roles as guarantors of human rights. The recommendations within the report cover all the main areas that were raised at the September meeting of the Cross-Party Group.

Action - Bob's letter will be shared with the group

**Bob/
SPPC**

2.3 Approval of minutes of last meeting

The minute of the meeting of Wednesday 5 September was approved.

3. Presentations and Discussion: Education needs for children's palliative care in Scotland: scoping and recommendations

Jayne Grant, Clinical Nurse Manager at CHAS introduced Dr Cari Malcolm, Lecturer (Child Health) at Napier University, who shared with the group some of the key findings from their scoping exercise to inform the development of an education strategy for CHAS. The speakers' PowerPoint slides will be circulated with the minute.

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

- Children who need very specific support from staff to enable them to communicate.
- Staff requirements for training in communication relating to anticipatory care planning and breaking bad news.
- The potential to disaggregate the 'general public' category of people requiring education into some key influential populations, for example 'media' and 'politicians'.
- The stresses arising when sensitive situations (such as those experienced by those close to and caring for Charlie Gard and Alfie Evans) gain a high

profile in the media. The staff involved in such cases cannot respond to criticisms, due to confidentiality rules.

- The need for MSPs to be educated about some relevant issues in children's palliative care in case they are ever called upon to be part of decision-making in sensitive or controversial cases.
- The importance of staff wellbeing in all care settings, including self-care and proactively caring for the workforce.
- PELICAN – the new managed clinical network for children's palliative care in Scotland.

ACTION: Consider 'staff well-being' as a potential future meeting topic for the cross-party group

SPPC

4. Brexit and Palliative and End of Life Care

The group discussed Brexit and its potential impacts on Palliative and End of Life Care, including the following issues:

- The impact that questions of residency rights are having on the health and social care workforce. Many staff have already left, and if this continues a situation will quickly arise where certain care home and care at home organisations will no longer be able to function.
- The likelihood of unreliable supplies of medicines following Brexit.
- The impact that Brexit will have on UK participation in research.
- The difficulties in mitigating against the risks of Brexit because it is all so beyond our control.
- The Migration Advisory Committee (MAC) report whose conclusions seem to be at odds with the content of the rest of the report.
- The MAC are currently seeking evidence to help inform their review of the shortage occupation list. Scottish Care and others are co-ordinating their responses to this consultation.

The Cross-Party Group would be supportive of a SPPC response to the MAC consultation which feeds in as appropriate the concerns discussed at this meeting.

ACTON: SPPC will consider submitting a response to the consultation and update the cross-party group at the next meeting.

5. Dates of Cross-Party Group Meetings in 2019

- Wednesday 13 March: Committee Room 1
- Wednesday 05 June: Committee Room 6
- Wednesday 04 September: Committee Room 4
- Wednesday 04 December: Committee Room 4