

Cross-Party Group on Palliative Care

Hybrid Meeting

Tuesday 24 September, 6.00-7.30pm, Scottish Parliament meeting room Q1.03 and on MS Teams

Approved Minute

In attendance at parliament:

Bob Doris MSP	
David Cameron	Office of Bob Doris MSP
Denis Agnew	St Margaret of Scotland Hospice
Belinda Hacking	NHS Lothian
Erna Haraldsdottir	Queen Margaret University
Mark Hazelwood	Scottish Partnership for Palliative Care
Oscar Hazelwood	Long Covid Scotland
Rebecca Patterson	Scottish Partnership for Palliative Care
Clare Murphy	St Margaret of Scotland Hospice
Gillian Wright	Researcher in Medical Ethics

In attendance remotely:

Miles Briggs MSP
Audrey Nicoll MSP
Stephen Kerr MSP
Alison Graham from Ash
Reagan's office

Further remote attendance was noted on MS Teams, automatically deleted after 7 days, before a formal note was taken.

Apologies:

Jackie Baillie MSP	
Rhoda Grant MSP	
Paul O'Kane MSP	
Marie McNair	
Scott Davidson	NHS Greater Glasgow and Clyde
Rob Gowans	The ALLIANCE
Donald Macaskill	Scottish Care
Kelly Moffat	Queen Margaret University
Maureen O'Neill	Faith in Older People
Elaine Stevens	International Association of Palliative Care Nurses
Ellie Wagstaff	Marie Curie

Agenda item 1: Welcome, introduction and apologies

Bob Doris welcomed attendees to the meeting, everyone introduced themselves either in person or in the MS Teams chat.

Agenda item 2: Approval of the minute of the previous meeting of 29 November 2023

Bob Doris explained that due to extended Parliamentary business the Cross Party Group on Palliative Care meetings of 19 March 2024 and 25 June 2024 were postponed. The group approved the minute of the meeting of 29 November 2023 as a correct record. The AGM had been held on 25th June 2024 and a draft minute of that meeting will be circulated alongside the draft minute from today's meeting.

Agenda item 3: Presentations and Discussion

Value-based Care at End of Life:

Professor Sir Muir Gray CBE sent his apologies but had prepared a short video introducing value-based care at end of life.

Kenny Steel, CEO Highland Hospice and Michael Loynd, Macmillan Clinical Programme Manager, End of Life Care Together, NHS Highland gave a presentation on the End of Life Care Together Programme in the Highlands and the report *Supporting end of life care in NHS Highland: Accounting for Value*. (Slides available here: [Scottish Partnership for Palliative Care | Value-based Care at End of Life](#))

Discussion and Questions

The following issues were discussed:

- The challenges of working within a system resistant to change and breaking a cycle of spending money reactively. Working outside 'the system', not being bound by each financial year, and finding people willing to work together has been key in Highland.
- The importance of measuring outcomes both locally and nationally, with hopes that some of the learning from Highland can help to inform national work on measuring outcomes.
- The End of Life Care Together report has endeavoured to be clear about cost savings, for example separating out the costs of the palliative care helpline and response service from other figures provided in the report.
- The need to overcome geographical barriers to deliver a responsive palliative care service at home. This requires flexibility, redistribution of money, and collaboration across all kinds of different organisations – no single organisation can solve this on its own.
- Though End of Life Care Together has illustrated resource savings, this doesn't mean that funding is now flowing differently – the system is very resistant to change, and there is still a prioritisation of healthcare over social care. Though there's much support from statutory partners, the mechanisms for change don't seem to be in place and a lot of work is still required.
- The importance of engaging with GPs.
- The role of the Helpline in helping to address people's psychological needs, often giving families the confidence to decide that hospital admission isn't the right thing for them.

- The potential of a shared digital care plan to change how people experience palliative care.

ACTION

Bob Doris will work with the speakers and the secretariat to draft a letter to Scottish Government drawing attention to the End of Life Care Together model as something from which learning can be drawn at a Scottish level.

Agenda item 4: Update on the Right to Palliative Care Bill consultation

Amy Dalrymple, Associate Director for Policy and Public Affairs at Marie Curie provided an update on the progress of the Right to Palliative Care bill.

Marie Curie is working closely with Miles Briggs, the MSP leading on the bill, but also with other MSPs from across parliament for a truly cross party approach. The draft bill went out for consultation at the beginning of June. There have been around 75 responses - around two thirds from organisations and the rest from individuals. The responses are currently being independently analysed by Sam Quinn at Glasgow University, and it is expected that this will be complete by mid October. The analysis and the consultation responses will be published at the same time.

Marie Curie has also been running a series of round table discussions on different themes that have come up pre and post consultation, chaired by various MSPs. The write up of the themes from these round tables will be published at the same time as the consultation responses and analysis.

Marie Curie are also exploring what other legislative vehicles there might be to take forward the right to palliative care, including the National Care Service Bill. The Human Rights Bill wasn't in the Programme for Government, so that is no longer an avenue, and it isn't clear what new legislation around human rights there might be before the election in 2026.

This work has highlighted some key issues, including:

- Resourcing of palliative care and how to ensure that expectations of a 'right to palliative care' can be met. This about structures, processes and skills as well as money.
- The need to recognise that palliative care is bigger than end of life care or specialist palliative care.

Miles Briggs MSP updated the group that he's had confirmation of a meeting with Jenny Minto on 31 October to discuss findings and input. He hopes to have an event in parliament to share findings, and also to explore what other opportunities there might be in the rest of the session to get this taken forward in some way.

Agenda item 5: Any other business.

No further business was discussed.

Agenda item 6: Date of the next Cross Party Group meeting

The date of the next meeting will be circulated to the group once it has been chosen.

Update: The next meeting of the cross party group will take place in the Scottish Parliament in Meeting Room Q1.04 on Wednesday 4 December 2024 from 6.00pm – 7.30pm.