

# Cross-Party Group on Palliative Care

Wednesday 29 November 2023, 6.00-7.30pm in Q1.04  
and on TEAMS

## Meeting note

### **In-person attendees**

Bob Doris MSP Scottish Parliament  
Marie McNair MSP Scottish Parliament  
Miles Briggs MSP Scottish Parliament  
Denis Agnew St Margaret of Scotland Hospice  
David Cameron Office of Bob Doris MSP  
Amy Dalrymple (speaker) Marie Curie  
Rob Gowans The ALLIANCE  
Mark Hazelwood Scottish Partnership for Palliative Care  
Isaac Hulse Office of Rhoda Grant MSP  
Claire Murphy St Margaret of Scotland Hospice  
Juliet Spiller Marie Curie  
Ellie Wagstaff Marie Curie

### **Remote Attendees:**

Kirsty Boyd Scottish Government  
Sophie Bridges Chest, Heart and Stroke Scotland  
Sandra Campbell Macmillan/ SAS  
Patricia Clifford Member of the Public  
Margaret Mary Cowan Kilbryde Hospice  
Pauline Ellison Scottish Partnership for Palliative Care  
Joy Farquharson St Andrew's Hospice  
Nicola Gordon Royal College of Nursing  
Donna Hastings St Columba's Hospice Care  
Helen Malo (speaker) Hospice UK  
Gordon Macdonald Care not Killing  
Jacqui Marwick Cruse Scotland  
Sandra McConnell NHS Lanarkshire  
Clare McGowan NHS Greater Glasgow and Clyde  
Jude Meryl Soul Midwives Scotland  
Sarah Mills University of St Andrews  
Aileen Morton Hospice UK  
Dot Partington St Columba's Hospice Care  
Kirsten Patterson NHS Tayside  
Allie Ramsay NHS Fife  
Meher Shagufta Playlist for Life  
Dalene Steele NHS Ayrshire and Arran  
Kenny Steele Highland Hospice  
Jackie Stone St Columba's Hospice Care  
Gillian Wright Care not Killing

### **Apologies:**

Jackie Baillie MSP Scottish Parliament

## APPROVED MINUTE

Stephen Kerr MSP Scottish Parliament  
Susan Bolt Scottish Government  
Liz Forbat University of Stirling  
Gillian Green St Vincent's Hospice  
Bridget Johnston NHS Greater Glasgow and Clyde  
Marie Manzi Macmillan Cancer Support  
Maureen O'Neill Faith in Older People  
Rebecca Patterson Scottish Partnership for Palliative Care  
Ross Sanderson Royal College of Nursing  
Louise Scott Scottish Government  
Niki Stark Royal College of Nursing  
Elaine Stevens International Association of Nurses in Palliative Care  
Julie Stuart NHS Grampian  
Michael Veich Care for Scotland  
Ashleigh Ward NHS Forth Valley

## Agenda item 1

### **Welcome, introduction and apologies**

Bob Doris MSP welcomed attendees to this hybrid meeting. There were three MSPs present – Bob Doris (convenor), Marie McNair (Deputy Convenor) and Miles Bridges. A list of attendees and apologies are noted above.

## Agenda item 2

### **Approval of the minute of the previous meeting of 28 June 2023**

The minute of the previous meeting of the group of 28 June 2023 was approved and adopted as an accurate record of the meeting.

## Agenda item 3

### **Matters Arising:**

#### **3.1: Update on Bereavement Summit:**

Mark Hazelwood updated the group. The Scottish Bereavement Summit report was published in July, and Rebecca Patterson and Donald Macaskill sent a copy to Maree Todd, Minister for Social Care, Wellbeing and Sport, requesting a meeting to discuss the report's recommendations. In reply, Rebecca and Donald were invited to a meeting with SG colleagues from some of the various departments with some responsibility for bereavement (including mental health and youth justice), and some positive discussions took place about how SG might start thinking about the role it can play in supporting the recommendations. A follow-up meeting with officials will take place later this week, and meeting with Maree Todd has been scheduled for December.

One of the key pieces of feedback from the Bereavement Summit attendees was that they didn't want to produce another report that would gather dust on a shelf. In response to this, GLGDGG and the Scottish Bereavement Charter Group are planning a series of 'moving from talk to action on bereavement' events. The first of these will take place on 23rd January 2024 on Zoom and will focus on improving signposting to bereavement information and support. The hope is that if every organisation represented at the meeting commits to

taking one action, together we can start to achieve meaningful change. We can circulate a link after the meeting so people can sign up/spread the word.

### **3.2: Update on Hospices/ Hospice at Home:**

The Convenor updated the group that there has been ongoing cross party work relating to the hospice sector, the main point arising from which is that it is clear that there needs to be a longer-term sustainable financial underpinning of the sector, however there is currently an absence of detail relating to that. However following a number of hospice visits, meetings and discussions, the Scottish Government is considering these issues. Those involved in taking this forward through the cross party work wait in anticipation for the publication of the Scottish Budget for 2024 to 2025 which is expected to be published on 19 December 2023.

## **Agenda item 4**

### **Presentations and discussion:**

#### **Exploring the potential for a legislative underpinning to improve palliative and end of life care in Scotland**

**Helen Malo**, Policy and Advocacy Manager Scotland, Hospice UK delivered a brief presentation from a current and historic perspective. Presently there are no duties around palliative care but a number of pieces of legislation relate to and impact on palliative care from *The Social Work (Scotland) Act 1968* which introduced a duty on local authorities to assess community care needs and deliver packages of care to the *Health and Care (Staffing) (Scotland) Act 2019* (which will be enacted in April 2024) which does not mention explicitly palliative care but is around ensuring appropriate staffing for safe, effective and high-quality care relating to NHS services as well as Registered Care services which includes care homes.

Historically – In 2010 there was an attempt to introduce a specific Palliative Care (Scotland) Bill by Gill Paterson MSP as a Member's Bill (originally proposed by Roseanna Cunningham MSP who was unable to take this forward due to her appointment then as Minister for Environment) which originated from evidence that palliative care services varied considerably across Scotland in terms of access, provision and quality. The Bill sought to place Scottish Ministers under a statutory duty to provide palliative care for those with life-limiting conditions and their family members, and to set up reporting arrangements so that provision could be monitored by the Scottish Parliament. The proposed Bill would also complement *Living and Dying Well* a national action plan for palliative and end of life care in Scotland which was published in 2008. The Health and Sport Committee was appointed as lead Committee for Stage 1 scrutiny of the Bill, gathering wide range of evidence in support of and in opposition to the Bill. Helen then went on to discuss and compare some of that evidence. After much deliberation the Health and Sport Committee recommended by a majority that the Parliament should not agree to the general principles of the Bill. The Bill was therefore withdrawn.

In England the 2022 Health and Care Act introduced new legislative measures that aim to make it easier for health and care organisations to deliver joined-up care for people who rely on multiple different services. New Integrated Care Boards now have a duty to commission services to meet the needs of their population – an amendment was later included to include

palliative care which means there is now a statutory requirement for the provision of palliative care services by these Care Boards.

Slides from this presentation are available on the SPPC website: [link](#)

In Scotland there is a general duty to provide appropriate medical and care services and in 2016 certain functions including the provision of palliative care services were delegated from Health Boards to Integrated Joint Boards. An advice note to support the strategic commissioning of Palliative and End of Life Care by these Boards was published in 2018 (not statutory legislation).

**What are the key changes needed to improve palliative and end of life care and what role could new legislation play in bringing these about?**

**Amy Dalrymple**, Associate Director for Policy and Public Affairs, Marie Curie Scotland then went on to discuss the current context. The opportunity to have a Member's Bill is potentially around having statutory legislation which describes a right to palliative care for people where the SG can decide which organisations have the obligations to fulfil that right and ensure that right is realised. Fundamentally the individual is identified as needing palliative care, has those needs assessed and has the right to have those needs met. That framing makes it important to have it in primary legislation rather than it being a delegated function that is an organisational responsibility to provide.

The opportunity of a pre-Member's Bill consultation is hugely important allowing the opportunity to provide discussions and get stakeholder input. There are other pieces of legislation currently passing through parliament or in development which could (but don't currently) make reference to palliative care - the National Care Service Bill and the prospective Human Rights Bill. The consultation around exploring having a right to palliative care and what that means is fundamentally important to everyone. Now is a good time to do this because of these other ongoing main pieces of work. To help structure a discussion, Amy posed three questions to attendees using Slido (a platform that allows participants to answer questions during a meeting using a link and code).

The Slido questions and responses can be accessed using this link: <https://www.palliativecarescotland.org.uk/content/publications/slido-responses-from-291123-CPG-meeting-002.docx>

The responses should inform: what are the issues we are trying to address? who it is for? how might it be done? what might the role of legislation be?

Main points from the ensuing discussion included:

- At the recent Scottish Cancer Conference 2023 there was a breakout session related to care treatments – palliative care was seen as a care treatment which creates an opportunity for people to decide that palliative care is right for them and their family, eg work in NHS Fife, Macmillan's supportive care initiative etc.
- The National Care Service has the potential to improve the local planning and commissioning of palliative care.
- Statutory duties do not always drive change.

- If things are being done properly already there is no extra 'ask' (no extra resource required)
- Stage 1 of the National Care Service (Scotland) Bill is expected in January 2024 with Stage 2 amendments taking place before summer recess
- The desire/ appetite to introduce a Member's Bill was questioned but it was agreed that this would highlight to SG the need to establish: a statutory framework for commissioning; a proper mapping of palliative care services in Scotland (NB: Mapping of palliative care in Scotland is currently being undertaken to underpin the new strategy with surveys of adult specialist services, HSCPs, NHS Boards and services for children and young people); a right to palliative care etc.
- If we wait for the next (non-legislative) initiative to make a difference the risk is we will be sitting here in 10 years' time having the same conversations/ arguments
- There is great concern about the Assisted Dying legislation – surely this cannot be taken forward without an underpinning of legislation for the right to palliative care
- From a nursing point of view there is far too much variation in access to services across Scotland right now – there are a lot of areas of good practice whilst others don't do so well mainly because of a lack of resources; the status quo is not good enough and this is a great opportunity to raise awareness and make things much more equitable across the country; one size does not fit all but more equitable access to services is what is needed and raising awareness via a Member's Bill would definitely do that
- Legislation can empower people – guidance is not enforceable
- Taking forward a Member's Bill would provide a lot of opportunities around promoting the right to palliative care – a consultation would help raise awareness of palliative care across all parties and help move it up their agendas
- There has to be clarity over which population this right is for – if it's for all people then that route is though identification of people with a palliative need (less than half of those who would benefit from palliative care are currently being identified) or those with a palliative diagnosis
- If SG legislates for a right it still does not have a statutory duty to provide that right – that needs to be remedied quickly
- Palliative Care is included in the Cancer Strategy – might be interesting to have a Slido Q&A related to this at a future XPG group meeting on Cancer
- Meeting psychological needs for the palliative care population is hugely under-resourced in Scotland; any rights-based approach should consider access to interventions around the emotional burdens/ high-symptom burdens for this population. There is a place for Third Sector interventions for psychological needs but these should also be addressed within the NHS core services too. Financially psychological interventions are cost effective – they reduce unscheduled care, bed days, use of medication etc – but provision is inadequate throughout Scotland.

Useful comments made in the chat by virtual attendees would also be taken onto consideration.

There was a general feeling across the group members that taking forward a Member's Bill would be a good idea. A Member's Bill can only be in the name of one MSP even where it has cross party support. This is being looked into by those involved in discussions with Amy.

APPROVED MINUTE

Sue Webber MSP is taking forward a members business debate on Hospice Funding the following Wednesday, 06 December 2023.

## Agenda item 5

### **Any other business**

On this occasion no further business was raised.

## Agenda item 6

### **Date of the next Cross Party Group meeting**

The next hybrid meeting will take place sometime in Q1 2024. Details to follow.