

Joint Meeting of the Cross Party Group for Hospices & Palliative Care and the Cross Party Group for Funerals & Bereavement

Thursday 18 October Ty Hywel, Conference Rooms C&D

Draft minutes

Attendance

- Mark Isherwood MS (chair)
- Deborah Smith, Wordsmith Communication (Secretary – CPG F&B)
- Matthew Brindley, Hospice UK (Secretary – CPG H&PC)
- Kim Bird
- Terry Tennens, SAIF
- Kathy Riddick, Humanists UK
- Andrew Judd, NAFD
- Rachel Bradburne, NAFD
- Philip Blatchly, PR Blatchly
- Carol Humphreys, Care for the Family
- Maxine Johnson, Cruse Bereavement Support Wales
- Stephen Tom, Philip Tom & Sons,
- Rhys Price, Gwilym Price
- Trystan Pritchard, St David's Hospice
- Emma Saysell, St David's Hospice Care
- Catrin Glyn, Carers Trust Wales
- Rachel Bradburne, NAFD
- Tomos Evans, Marie Curie
- Glenn Page, Macmillan Cancer Support
- Gethin Rhys, Cytûn: Churches Together in Wales
- Huw Owen, Ty Hafan/Ty Gobaith Children's Hospice
- Jon Antoniazzi, Marie Curie
- Phillip Blatchly, Phillip Blatchly & Sons
- John Adams, Perry & Phillips
- Anna-Louise Marsh, Covid-19 Bereaved Families for Justice Cymru
- John Moss, National Bereavement Framework Programme Manager
- Liz Booyse, Chair of Hospices Cymru
- Ceridwen Hughes, Sam but Different
- Mary Mitchell, Lived Experience
- Katie Reade, Hospice UK
- Dr Sally Stringer, Same but Different
- Laura Hugman, Paul Sartori Hospice at Home
- Grant Usmar, Hospice of the Valleys
- Tash Wynne, Marie Curie

Welcome and introduction

Mark Isherwood MS, chair of the Cross Party Group for Hospices and Palliative Care and the Cross Party Group for Funerals and Bereavement, welcomed those present at the meeting at Ty Hywel and those joining online for the first joint meeting of the Cross Party Groups for Hospices & Palliative Care, and Funerals & Bereavement.

Mark explained that the aim of the meeting was to bring together two groups with distinct objectives and audiences, but a shared connection on issues relating to end of life care – both for those who die and those who are closest to them, enabling the combined membership to share information and spark discussions that might lead to collaboration between the two Groups.

Apologies

Deborah Smith and Matthew Brindley reported that apologies had been received from:

- Darren Millar MS

- Mike Hedges MS
- Jane Dodds MS
- Llyr Gruffyd MS
- Ahmed Alsisi, White Rose Funerals
- Graham Swan, National Association of Funeral Plan Providers
- Kate Edwards, Pathway Associates
- Emma Kneebone, 2Wish
- James Cooper, Together for Short Lives
- Maxine Johnson, CRUSE
- Dr Idris Baker, National Clinical Lead for Palliative and End of Life Care
- Heledd Fychan MS
- Mabon ap Gwynfor MS
- Anna Tee, Macmillan Cancer Support

Minutes of previous meetings; matters arising

Deborah reported that the Funerals & Bereavement Group met most recently on 11 July. Minutes of the meeting had been sent out to members in advance of today's meeting. There were no questions or corrections to the minutes from the floor and acceptance of the minutes were proposed by Phil Blatchly and seconded by Terry Tennens.

The Hospices & Palliative Care Group last met on 13 July 2023. Matthew Brindley reported that minutes of the meeting had been sent out to members in advance of the meeting. There were no questions or corrections to the minutes from the floor and acceptance of the minutes were proposed by Grant Usmar and seconded by Liz Booyse.

CPG for Hospice and Palliative Care: Ongoing and arising actions

Date	Action	Status
13 th July	CPG to write to the Minister for Health and Social Services regarding challenges Welsh hospices are facing	Outstanding
18 th Oct	CPG to write to Chief Exec of Betsi Cadwaladr UHB regarding issues faced by St David's Hospice	
18 th Oct	CPG to write to the Chair of the Senedd Health and Social Care Committee making them aware of the What Matters Most project and the importance of ensuring people's lived experiences of palliative and end of life care are central to decision-making.	
18 th Oct	Explore options for Anna-Louise to share the CPG Inquiry report as part of modules 2 and 3 of the UK Covid-19 Inquiry, alongside approaching Altaf Hussain MS, who sits on the COVID Committee in the Senedd.	

CPG for Funerals and Bereavement: Ongoing and arising actions

Date	Action	Status
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10 July	Rearrange meeting Law Commission review team.	Now awaiting input on dates from Law Commission team
10 July	Mark Isherwood actioned a letter to the First Minister and relevant ministers highlighting the important potential of digital autopsy and lack of access for the people of Wales.	
18 Oct	Mark Isherwood MS suggested an approach to Altaf Hussain MS, who sits on the COVID Committee in the Senedd, regarding funeral sector participation in the COVID Inquiry.	
18 Oct	Mark Isherwood actioned a letter to the Welsh Government Education Minister, on behalf of the CPG, to highlight the bereavement in education campaign.	
18 Oct	Deborah Smith to put John Adams and Gethin Rhys in contact re: bereavement in education campaign.	

Speaker: The challenges facing Welsh hospices and the Welsh Government Phase 3 Palliative and End of Life Care Funding Review

Liz Booyse, Chair of Hospices Cymru, highlighted the funding request for hospices currently being considered by Welsh Government. She also set out some of the challenges facing Welsh hospices and provided an update on the Welsh Government Phase 3 Palliative and End of Life Care Funding Review. She highlighted the potential risk of the loss of talented staff and the ongoing issue of fair and equal pay in Welsh hospices. Mark Isherwood MS noted the Budget Statement that had been published the previous day, but that it was not yet clear how the funding would be sliced.

Trystan Pritchard made the point that it remained a postcode lottery in terms of access to support and funding for families, and that despite being told they were ‘part of the family’ in terms of the bereavement framework, hospices often felt like outcasts – and not valued. He also emphasized that whilst it was often viewed by health boards that they were making a 25 percent contribution to the funding of hospices, he instead sought to ensure they understood that hospices were offering them a 75 percent discount in their costs of providing end of life care. He described how Betsi Cadwaladr UHB is cutting approximately £150,000 from their funding at a time when the Health Board has closed its own specialist palliative care beds and expecting St David’s to meet the shortfalls. The funding review should address these immediate pressures and the postcode lottery of hospice funding in Wales, alongside building a more sustainable model for the future.

Mark Isherwood asked if other hospices were facing similar pressures. Emma Saysell from St David’s Hospice Care said they weren’t planning cuts and were fortunate that their Health Board had provided an uplift. Laura from Paul Sartori Hospice at Home said they haven’t had an uplift from their Health Board and were in an uncertain position waiting for it to produce a new commissioning framework.

Andrew Judd highlighted the issue of anticipatory grief, and the important role of hospices in supporting those close to a person in hospice care ahead of bereavement.

Mark Isherwood and the CPG actioned writing to the Chief Executive of Betsi Cadwaladr UHB regarding the issues faced by St David’s Hospice. They also said they would keep in touch with Hospices Cymru and potentially write to the Health Minister about the challenges facing Welsh hospices subject to developments with the funding review.

Speaker: Implications of the Fuller Inquiry into the care of deceased people, Rachel Bradburne (NAFD)

Rachel Bradburne, Director of Policy, and Public Affairs for the NAFD provided an update on the independent inquiry into the actions of former hospital electrician David Fuller, in Kent, which was now expanding its work to focus on how deceased people are cared for, not only in hospitals, but in community settings too.

She outlined the potential lessons and regulatory outcomes for Wales and emphasised that this has implications for any setting where a deceased person might be looked after, even if for only a short period of time and so was relevant to representatives of both cross party groups.

Rachel set out the work that was going on within the funeral sector regarding oversight of standards of care, the likely timescales and outcomes and noted that although the inquiry was focused in England, any recommendations which came from it were likely to be considered across the UK.

Kim Bird asked if the Inquiry would consider issues such as the involvement of families and communities in customs such as ritual washing. John Adams supported this point and offered a case study about the funeral of a young man who had died by suicide and the work that his funeral business had done to change the atmosphere in the mortuary through the use of candles and music to make it less clinical and more welcoming environment for his family as they had wished to be involved in his care. They both emphasized the importance of ensuring that any future guidance does not make this kind of family/community involvement in care of deceased impossible.

Rachel Bradburne also noted that it was the Inquiry's intention to consider ALL settings where deceased may be cared for and therefore the Inquiry team are likely to also consider the home. She said that bereaved people and their experiences were important to the Inquiry team and would continue to feature strongly. She concluded that there was a risk that, given the timing of the inquiry, the opportunity for any significant change could be lost as a result of the General Election next year.

Speaker: Introduction to the *What Matters Most* visual storytelling project by Ceridwen Hughes

The meeting was joined by Same but Different photographer and director, Ceridwen Hughes, to introduce the What Matters Most project, inspired by her own experience of end-of-life care when her mother died in 2020. Unfortunately, Ceridwen had lost her voice and so her presentation was given by Dr Sally Stringer.

Through photography, film, and written narratives of the experiences of those receiving and delivering care, Sally explained how Ceridwen had captured the experiences of those living with dying and the caregivers involved in providing care and support, with the aim of improving end of life care.

In the discussion which followed, Mary Mitchell noted how fulfilling the project had been to be involved with.

Andrew Judd expressed his admiration for the project and how humbling and moving it was to watch the film. He spoke about the importance of the passing of care from those involved in hospice and other palliative care settings to funeral directors and the importance of trust.

Matthew Brindley offered thanks to partners such as Marie Curie and hospice volunteers for their engagement with the project and said the project had been borne out of a desire to capture real life experiences and highlight key issues to the Welsh Government in respect of the current National Programme and funding reviews.

Mark Isherwood and the CPG actioned writing to the Chair of the Senedd Health and Social Care Committee making them aware of the project and the importance of ensuring people's lived experiences of palliative and end of life care are a central part of decision-making.

Discussion: Experiences of bereavement support in Wales and how it can be improved

Anna-Louise Marsh, Covid-19 Bereaved Families for Justice Cymru, provided an update to the meeting about the COVID Inquiry, and the representations made on behalf of 500 families in Wales who were bereaved, with many not receiving appropriate bereavement support.

The group had called for a dedicated inquiry for Wales, which had been refused but they are now core participants for the UK-wide COVID Inquiry.

She highlighted concerns that during the pandemic, Aneurin Bevan Health Board had permitted a photographer into the mortuary to capture the experience of the pandemic, but the implications of this for the rights of the deceased and their families were ignored – even if individuals could not be identified. Rachel Bradburne noted that the Human Tissue Authority might have an interest in this if the dignity of the deceased had been compromised.

Anna-Louise thanked funeral directors for being unsung heroes during the pandemic as they were often the only people bereaved families had support from and agreed with Andrew Judd on his point about anticipatory grief.

She noted that she was keen for there to be mandatory bereavement training for all healthcare workers and was working closely with John Moss on this.

John Moss, National Bereavement Framework Programme Manager, provided an update on the National Bereavement Framework, reminding attendees of the history of the project from the review of bereavement services in Wales in 2019, the launch of the framework in 2021 and current work to create national bereavement pathways in respect of the baby loss and children. John also noted that there was work to create a bereavement standard, and this would be the first quality measure to be included in NHS Health Board Performance frameworks.

Terry Tennens and Andrew Judd noted that they had participated in one of the steering group meetings.

Gethin Rhys asked what had happened to Compassionate Cymru. John Moss responded that work was underway to reestablish it, and ensure the network remains in place.

Anna-Louise Marsh offered to send the report of the Cross Party Group for Hospices and Palliative Care to the UK COVID Inquiry. It is believed that palliative care will be covered by the Inquiry in Autumn 2024.

Mark Isherwood MS suggested also approaching Altaf Hussain MS, who sits on the COVID Committee in the Senedd.

Discussion: Supporting and educating young people about bereavement

John Adams, Perry & Phillips Funeral Directors in Shopshire joined the meeting to introduce his campaign to see bereavement and loss added to the National Curriculum. John explained how he lost his mum at 12 and this experience, together with his role as a funeral director, has shaped how he supports families through bereavement – and motivated him to launch a campaign during his year as NAFD President (2022-23). To date he has discussed the topic with the King, secured 11,000

signatures and a debate in Parliament – and a commitment for the topic to be reviewed by the Department for Education.

It was noted by Jon Antoniazzi that there had been positive work in partnership with Marie Curie on teacher training in Northern Ireland that might be work considering as a model.

It was also highlighted by Gethin Rhys that there were options within the RSE curriculum potentially to include this topic and Deborah Smith offered to follow this up after the meeting and put John Adams and Gethin Rhys in contact.

Mark Isherwood offered to write to the Welsh Government Education Minister, on behalf of the CPG, to highlight the campaign.

Any Other Business

There were no items raised under Any Other Business.

Dates for Future Meetings

Matthew Brindley and Deborah Smith noted that the next meetings for both Groups would fall in January, with dates to be circulated as soon as possible.