

# Joint Senedd Cross Party Group on Hospice and Palliative Care/Funerals and Bereavement

## Minutes

2 April 2025

Attendance:

Mark Isherwood MS (Chair)	Liz Booyse, City Hospice
Matthew Brindley, Hospice UK (Secretary)	Natasha Davies, Marie Curie
Rebecca Aylott, NAFD (Secretary)	Irfon Rees, Ty Hafan
Huw Owen, Ty Gobaith/Ty Hafan	Lesley Bethell, Compassionate Cymru
Tracy Jones, Tŷ Hafan	Andrea Powell, Cruse Bereavement
Thea Brain, Care Forum Wales	Dafydd Huw, Royal College of Psychiatrists
Tomos Evans, Marie Curie	Baroness Iloria Finlay
Darren Rutland, HDA	Hilary Watson, MS Society
Heather Ferguson, AGE Cymru	Jen Mills, MND Association
Jack Sunderland, Caldecott and Sons	Laura Hugman, Paul Sartori Hospice at Home
Jodie Beck, Hospice UK	Mari Vaughan-Owen, Humanists UK
Lee Barnett, Sandy Bear	Alexander Owen, MS support staff
Martin Jones, Sandy Bear	Dr Sarah Davies, Consultant Physician, BCUHB
Philip Blatchly, Philip Blatchly Funeral Directors	Terry Tennens, SAIF
Steven Crane-Jenkins, BASW Cymru	Dr Jason Shannon, Lead Medical Examiner for Wales
Dr Victoria Wheatley, Palliative Care Consultant, Hywel Dda UHB	Andrew Judd, NAFD
Eleanor Hunt, The Woollen Cwtch Company	Rachel Bradburne, NAFD
Tyler Troy	Doug Nairn, NAFD
Rhys Price, Gwilym C. Price Son & Daughters	Kathy Riddick, Humanists UK

Apologies:

Darren Millar MS	Janet Finch-Saunders MS
Jane Dodds MS	Llyr Gruffydd MS
Heather Hughes, 2Wish	Verity Sterling, Church in Wales
Lestyn Davies, Cytûn/Churches Together in Wales	Andy Goldsmith, Ty Gobaith/Hope House Children's Hospice

John Moss, Welsh Government Programme Manager for the National Bereavement Framework	Gethin Rhys from Cytûn/Churches Together in Wales
Carol Davies, HDA	Brendan Day, Greener Globe Funeral Standard
Paula Williams, Papyrus	Stephen Tom, Philip Tom & Sons
Revd Nicola Frail, MoD	

**Welcome from the Chair, Minutes from the previous meeting and matters arising**

Mark Isherwood MS welcomed everybody to the joint meeting, in particular guest speakers Baroness Finlay and Dr Jason Shannon for taking the time to present.

Minutes from the previous CPG for Funerals and Bereavement meeting were confirmed by [name of proposer not captured] and seconded by Philip Blatchly.

Mark Isherwood MS provided an update on matters arising from the CPG for Funerals and Bereavement:

- Firstly, that correspondence has been sent to confirm the Welsh Government’s position concerning the Law Commission’s project on Burial and Cremation, following the public consultation that closed in January.
- Secondly, that correspondence has been sent to the WLGA following the discussions that members had concerning digital post-mortem provision in Wales, on what consideration Local Authorities might have given to funding this.
- Thirdly, with the Welsh Government’s apology to bereaved families earlier this year regarding the delays being experienced with funerals and death certification, that it has been agreed to write to the Cabinet Secretary for Health and Social Care on these delays, and that it is hoped that comments from today's meeting will feed into this correspondence.

Minutes from the previous CPG on Hospice and Palliative Care meeting were confirmed by Liz Booyse and seconded by Tracy Jones.

Mark Isherwood MS updated members on matters arising from the last meeting of the CPG on Hospice and Palliative Care:

- The CPG wrote to the Cabinet Secretary for Health and Social Care regarding the challenges facing Welsh hospices, provision of children’s palliative care across Wales, and the impact of Further Faster on the delivery of palliative and end of life care in the community. The Cabinet Secretary provided a response on Welsh hospices and after a significant delay has only just responded on children's palliative care and Further Faster which will be shared with relevant members shortly.

**Spotlight on the Terminally Ill Adults (End of Life) Bill and its possible implications for palliative and end of life care in Wales with Baroness Ilora Finlay**

Baroness Finlay presented to the joint CPG on the Terminally Ill Adults (End of Life) Bill and its possible implications for palliative and end of life care in Wales.

Key issues discussed:

- Baroness Finlay described the amended Terminally Ill Adults (End of Life) Bill following Committee stage as being significantly weakened, especially in respect to key safeguards. She highlighted multiple issues with the Bill, including:
  - the changes required to the NHS Act
  - Welsh and other language barriers potentially impacting consent
  - the need for a law that is safe for everybody
  - existing challenges and gaps in accessing palliative care and the need to protect and improve what we've got
  - current palliative care workforce issues and potential future challenges if the Bill is implemented
  - problems within the Bill regarding doctors not being able to ask someone why they want to end their life
  - questions regarding the effectiveness of medicines prescribed to end a life
- Mark Isherwood MS thanked Ilora and said that the CPG had been made aware of the potential challenges for Welsh language speakers in the Bill and that the Senedd had voted in principle against assisted dying last year.
- Dr Victoria Wheatley described the challenges they're facing recruiting in palliative care in West Wales with a quarter of people not having access to a hospice bed. She said more resources need to be put into palliative care.
- Dr Sarah Davies said particular attention needs to be paid to the vulnerable people they care for, especially when considering changes to the Suicide Act. She also highlighted the existing challenges facing palliative care in North Wales.
- Dr Jason Shannon said that Medical Examiners could potentially play a key role in understanding people's experiences of assisted dying if it was introduced, and that if the Bill passes, it would require a change to the current notification of death regulations.
- Baroness Finlay responded that Medical Examiners don't have a role as the Bill is currently set out, highlighting concerns that errors may not be detected if the current legislation was introduced.
- Eleanor Hunt from The Woollen Cwtch Company described her poor experience trying to access palliative and end of life care for her father in mid-Wales. He was regularly asked to sign Do Not Resuscitate agreements when he was unwilling and while there was no intent, it felt coercive.
- Dafydd Huw from the Royal College of Psychiatrists said the college had a neutral position on the Bill but had concerns about language barriers.

- Baroness Finlay responded saying she was concerned that there was limited understanding and awareness of the Bill amongst Psychiatrists.

### **Update on the Medical Examiner Scheme in Wales and how it fits with the wider strategy of bereavement care with Dr Jason Shannon, Lead Medical Examiner for Wales**

#### Key issues discussed:

- Dr Jason Shannon noted the importance of giving bereaved families the opportunity to ask questions about the cause of death and to raise any concerns or issues that they might have. He commented that in Wales, more bereaved families take the opportunity of speaking to the Medical Examiner (ME) about potential care concerns than anywhere else in the UK. Dr Jason Shannon commented that the service provides a voice for bereaved people, which is guaranteed and built in through the independence and impartiality of the Medical Examiner.
- Dr Jason Shannon acknowledged that the median time to register a death in Wales is currently too high and has been since approximately December 2024, where the whole system started to struggle, and noted that the Welsh Government is looking at what the issues and their solutions might be.
- Rachel Bradburne asked whether the NAFD and the wider sector can do anything further to assist as stakeholders, in addition to current engagement with the Welsh Government. Dr Jason Shannon replied that funeral directors in particular can support by ensuring that they are well informed on the process of death registration, including the role and responsibilities of the ME, to inform their work supporting bereaved families.
- Mark Isherwood MS asked about the sensitivity that can be given to faith and cultural issues, and Dr Jason Shannon acknowledged that the ME Service recognises that there are a number of potential situations where cases may need to be processed more urgently, including faith requirements, and that the service successfully manages those cases.
- Dr Jason Shannon and Dr Sarah Davies commented the challenges of mitigating Attending Practitioner/ME scheduling and capacity issues, and that digitisation of the MCCD would likely assist with these challenges, along with resolving other interconnectivity problems within health boards.
- Rhys Price commented that everybody has a role to play to help streamline and make the process better for bereaved families. He also commented that while Medical Examiner officers try to help, funeral directors often have difficulties with the ME's 'telephone tree' phone system and trying to get updates on behalf of bereaved families, for whom funeral directors are acting as nominated representatives. He noted that there seems to be a lack of understanding among families as to why things are taking so long, and that better awareness of the process among doctors is needed. Dr Jason Shannon agreed to feed back comments regarding the 'telephone tree' system.
- Eleanor Hunt asked about expectations for winter planning and delays, and Jack Sunderland, a funeral director based in Wrexham, commented on the comparison of communication with ME services in Wales and in England. Dr Jason Shannon thanked Jack for his cross-border observations, and acknowledged the significant challenges that are being faced, particularly during the pressures of the recent winter period, which led to delays in death registration.

- Mark Isherwood MS and Rebecca Aylott agreed an action, to capture issues around digitisation, system connectivity and winter planning in follow up with the Welsh Government and with the UK Government. It was also agreed to invite a Coronial representative to a future meeting.

#### **AOB**

- It was agreed that a representative from Papyrus will present at the next meeting of the CPG for Funerals and Bereavement.
- Mark Isherwood MS confirmed that the next meetings of the respective CPGs will likely be held in July 2025, the details of which will be confirmed and circulated in due course by the respective secretaries.