

GTB Gofal Hosbis a Lliniarol 8 July 2021 8:30-9:30yb

CPG Hospice and Palliative Care 8 Gorffennaf 2021 8:30-9:30am

Cyfarfod Cyffredinol Cyntaf I Inaugural Annual General Meeting

Cofnodion | Minutes

Yn bresennol | Attendance

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|---------------------------|-----------------------|
| Mabon ap Gwynfor MS | Huw Irranca-Davies MS |
| Rhun ap Iorwerth MS | Mark Isherwood MS |
| Peredur Owen Griffiths MS | Darren Millar MS |
| Altaf Hussain MS | |

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| Jon Antoniazzi, Macmillan | Tracy Jones, Ty Hafan |
| Janette Bourne, Cruse Bereavement Care | J Phillips (on behalf of Jayne Bryant MS) |
| Dominic Carter, Hospice UK | Trystan Pritchard, St David's Hospice |
| Ryland Doyle (on behalf of Mike Hedges MS) | Gethin Rhys, Cytun |
| Catrin Edwards, Hospice UK | Emma Saysell, St David's Hospice Care |
| Lowri Griffiths, Marie Curie | Rhys Taylor (on behalf of Jane Dodds MS) |
| Steve Ham, Chair of the End of Life Board | Grant Usmar, Hospice of the Valleys |
| Iwan Hughes, Royal Pharmaceutical Society | Georgina Webb, Welsh Conservatives |
| Laura Hugman, Paul Sartori Foundation | Lynsey Wheeler, Hospice of the Valleys |
| Kim Jones, Hospice of the Valleys | |

Ymddiheuriadau | Apologies

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|-----------------------------|---------------------------------------|
| Janet Finch-Saunders MS | Andy Goldsmith, Ty Gobaith/Hope House |
| Tom Davies, Macmillan | Marika Hills, Macmillan |
| Bethan Edwards, Marie Curie | Iain Mitchell, St Kentigern |

Welcome from the previous Chair, and establishing a CPG Hospice and Palliative Care in the Sixth Senedd

- Mark Isherwood welcomed the group to the inaugural CPG Hospice and Palliative Care in the Sixth Senedd.
- Catrin Edwards talked the group through the CPG Hospice and Palliative Care in the Fifth Senedd legacy report, noting the achievements of the group, ongoing and forthcoming scrutiny work and work carried over from that group which the current group may wish to pursue.

Action: Chair to write to the Minister for Health and Social Services to asking her to acknowledge and respond to the CPG in the Fifth Senedd's report, 'The role of the Welsh

Government's Compassionate Cymru programme in building capacity and resilience in communities through and beyond the Covid-19 pandemic'

- CE talked the group through the proposed wording of the purpose of the CPG Hospice and Palliative Care in the Sixth Senedd, as registered with the Table Office. Tracy Jones suggested the amendment of ensuring that the group aimed to improve *palliative and* end of life care. There was discussion about the relevance of including "bereavement" specifically within the registered purpose; it was decided that, while bereavement is a core part of palliative care, this would constitute too great an overlap with another existing CPG. The group agreed the wording:
 - Maintain and develop understanding and interest by Members of the Senedd on issues affecting people who need hospice and palliative care, in the furtherance of improving palliative and end of life care for all in Wales.
- All those in attendance confirmed they wished to be members of the CPG Hospice and Palliative Care in the Sixth Senedd. CE maintained a list of Members of the Senedd and external organisations noting their apologies but wishing to be registered members of the CPG.
- Election of Officers as part of the AGM:
 - Mark Isherwood was proposed as Chair by Darren Millar, seconded by Huw Irranca-Davies, Mabon ap Gwynfor, Altaf Hussain and Rhun ap Iorwerth. Mark Isherwood elected as Chair.
 - Catrin Edwards put herself forward as Secretary. Seconded by Mark Isherwood. Catrin Edwards elected as Secretary.

Action: CE to submit registration papers to the Table Office.

Priorities for palliative Care in Wales 2021: an update – Steve Ham, Chair of the End of Life Care Board

Steve Ham explained that the existing End of Life Board continues until the National Programme for End of Life Care is put in place under the National Clinical Framework. Under the Board, work continues on:

- Working with the children's hospices on research into the prevalence and complexity of paediatric palliative care need in Wales
- Commissioned by Welsh Government to take forward a review of hospice funding. A steering group is being established with the view to completing the work by the Autumn
- Establishing a Steering Group for the National EOLC Programme, meeting this month
- Development of a Quality Statement for EOLC
- Stocktake of EOLC – a review of where we are based on progress made against the vision set out in the Sugar Report 2009. The Stocktake serves as a legacy statement from the current EOL Board
- Covid Emergency Funding for Hospices, leading to closer working with charitable hospices
- Overseeing the development of the National Bereavement Framework, including allocating funding under this Framework when finalised
- Overseeing the Compassionate Cymru programme. Macmillan have provided funding for a Programme Manager, which has helped to progress this work
- Building a business case for the digitisation of Advance Care Plans
- Developing Outcome Measures in partnership with Marie Curie, with a workshop scheduled for Autumn. Work on PREMs (Patient Reported Experience Measures) is ongoing

- Implementing the upgraded CaNISC
- Digitising the Wales-wide guidance, Care Decisions in the last days of life
- Supporting the recruitment of a Tier 4 Consultant in Paediatric Palliative Medicine to be based in North Wales

Discussion

Darren Millar MS inquired about the timeline for the hospice funding review; SH confirmed that this is scheduled to be completed in Autumn 2021.

MI noted that he led a debate in the final session of the Fifth Senedd on sustainable funding for children's hospices, which had cross-party support.

SH pointed out that the hospice funding review goes hand in hand with the prevalence research for paediatric palliative care.

MI noted that hospices are funded primarily by health boards and that there is significant variation in the allocation of funding by health boards across the country; is there discussion between health boards and Trusts regarding the funding of palliative care? SH confirmed that the hospice funding review would consider consistency and the variety of hospice service models.

In the chat, Trystan Pritchard highlighted the ongoing tensions that hospices navigate between local funding arrangements with health boards and the national steer.

Experience of care in a pandemic: a family's perspective and a nurse's perspective – Lynsey Wheeler and Kim Jones, Hospice of the Valleys

Kim Jones, Deputy Head of Clinical Services at Hospice of the Valleys, gave an overview of her experience on the frontline during the pandemic. This included:

- A move at first to contacting people by phone, especially patients with cancer. Nurses soon realised that there was a need to maintain face to face contact with families. This was especially the case for people with dementia and their carers, who were desperate for contact given that many other services had withdrawn.
- There was an increased caseload within the 14 care homes supported by the hospice. Some lost more than a third of their residents. Nurses supported dying people, the care home workers and the families of those who died.
- The Advanced Nurse Practitioner at Ysbyty Aneurin Bevan spend a significant amount of time communication by phone with the families and loved ones of people on the ward under her care.
- There has been a knock on impact for the hospice bereavement service. Not only have more people experienced a bereavement but these have been under complex circumstances with many feeling guilt as part of their grief.

Lynsey Wheeler shared her family's experience of the care given to them as her mum passed away from bowel cancer during 2020. Anne came home from hospital with a full package of care for six weeks. This included overnight respite every night, partly provided through Continuing Health Care funding and partly charitably funded by the hospice. The hospice supported Lynsey to live with her concerns about having mum home as she approached end of life, which meant they could spend precious time together towards the end.

Lowri Griffiths and Liz Andrews thanked Lynsey for sharing her story. LG noted the difference made to families when care wraps around them. This should be taken back to the End of Life Board.

J Phillips asked how the hospice was managing staff burnout. KJ said they are a small team with supportive managers. “Statutory services stepped back and we needed to step forward.” Providing clinical supervision for the team and colleagues in care homes has been essential. b

Developing the forward work plan for the CPG Hospices and Palliative Care

CE invited members to consider whether there are areas included in the papers presented in the meeting and beyond from their own areas of expertise that should form part of the CPG’s work programme for the coming year.

Action: Members to contact CE with suggestions.

CE talked to a paper shared with the group in advance with a proposal to undertake a deep dive into people’s experience of palliative care in the community during the pandemic. This would be with a view to informing any inquiry – at UK or Welsh Government level and Senedd Committee level – into the impact of the pandemic on people and the health and care sector, providing insight into an area that would otherwise not receive full attention from Senedd Committees.

Members agreed that this would be a helpful approach and added constructive suggestions. LG suggested that the deep dive should be extended to include the experience of care of people at the end of life in care homes. Emma Saysell agreed.

Action: CE to contact Care Forum Wales to engage their members.

Huw Owen expressed support for the deep dive and noted that there were opportunities for joint work with the CPG Dementia.

Action: CE and HO to follow up on joint CPG work.

Jon Antoniazzi noted that Macmillan’s joint work with the Welsh Ambulance Service Trust to care for people at end of life would be valuable work to capture as part of this deep dive.

Rhun ap Iorwerth pressed the need to move quickly with this work while people’s memories of care are fresh.

DM agreed that a deep dive would help to capture experiences such as those that had been shared in the current meeting.

CE suggested that it would be helpful to inform the Chair of the Health and Social Care Committee of the intended deep dive. MI agreed and further noted that the report from the CPG in the Fifth Senedd on the Welsh Government’s Compassionate Cymru programme should be shared also.

Action: Chair to write to Chair of the Health and Social Care Committee to inform of the proposed deep dive and the previous CPG report.

AOB

Nothing raised.

Meetings for the year to be circulated.