

GTB Hosbis a Gofal Lliniarol 27 Hydref 2022, 15.00-16.30 CPG Hospice and Palliative Care 27 October 2022, 15.00-16.30

Progress developing National Policy for Palliative and End of Life Care in Wales and spotlight on impact of cost of living crisis on hospices and care in Cymraeg

Cofnodion | Minutes

Yn bresennol | Attendance

Mark Isherwood MS	Altat Hussain MS
Rhun ap Iorwerth MS	

Ceridwen Hughes, Same But Different	Liz Booyse, City Hospice
Dominic Carter, Hospice UK	Trystan Pritchard, St David's Hospice
Matthew Brindley, Hospice UK	Lesley Bethell, Compassionate Cymru
Tash Wynne, Marie Curie	Grant Usmar, Hospice of the Valleys
Tracy Jones, Tŷ Hafan	Rhys Hughes, Rhun ap Iorwerth MS office
Emma Saysell, St David's Hospice Care	Gethin Rhys, Cytûn
Janette Bourne, Cruse	Angharad Davies, Ty Gobaith
Grant Usmar, Hospice of the Valleys	George Parish Wallace, Alzheimer's Society
Bethan Davies, Welsh Government	Eleri Morgan, Senedd
Andy Goldsmith, Ty Gobaith	Jon Antoniazzi, Marie Curie
Glenn Page, Macmillan Cancer Support	Bethan Edwards, Marie Curie
Tina Ahang, Together for Short Lives	Prof Chris Jones, DCMO Welsh Government
Dr Idris Baker, National Clinical Lead PEOLC	Rachel Williams, Parkinson's UK
Iain Mitchell, St Kentigern Hospice	

Ymddiheuriadau | Apologies

Peredur Owen Griffiths MS	Melanie Minty, Care Forum Wales
Heledd Fychan MS	Steve Parry, Nightingale House Hospice

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

Mark welcomed everybody to the meeting, in particular the guest speakers addressing progress developing national policy for palliative and end of life care in Wales, the impact of the cost of living crisis on hospices, and good practice providing hospice care in Cymraeg.

Minutes from the previous meeting were confirmed by Tracy Jones and seconded by Janette Bourne and Liz Booyse.

Mark updated members on progress against actions:

- Wrote to the Minister for Health and Social Services inviting her to this meeting and asking her what is being done to improve access to palliative care during the out of hours period, as highlighted by the evidence Ceridwen Hughes presented to the group before recess. Unfortunately, the Minister didn't specifically answer these questions in her written response and wasn't available to join the meeting, but she did ask Prof Chris Jones (DCMO) and Dr Idris Baker (National Clinical Lead for PEO LC) to attend on her behalf.
- Wrote to the Chief Executive of Betsi Cadwaladr Health Board regarding the same issues, but unfortunately their response failed to address the evidence heard by the CPG, in particular access to out of hours support.
- Two outstanding actions are to ask Hospices Cymru how they can work together with Health Boards to address the out of hours issues Ceri raised, and to invite the Association of Directors of Social Services Cymru to join this group to discuss how access to short breaks for children with life-limiting conditions and their families can be improved.
- Initial findings and recommendations from the soon to be published CPG inquiry report into experiences of palliative and end of life care in the community during the pandemic will be presented by Matthew for feedback.

Ongoing and arising actions

Date	Action	Status
27 Oct	Invite Association of Directors of Social Services representative to attend a future CPG session to talk about improving family access to respite	
27 Oct	Ask Hospices Cymru how they can work together with Health Boards to address the out-of-ours issues	
27 Oct	Update CPG inquiry report and publish before next meeting	
27 Oct	Consult with Ceridwen Hughes about how to respond to Minister and BCUHB letters and offers of support from Idris Baker and Chris Jones	
27 Oct	CPG to write to Welsh and UK Government's on cost of living impact on hospices and support	
27 Oct	Send Idris Baker and Chris Jones hospice cost of living survey	

Update and discussion on progress developing national policy for palliative and end of life care

Dr Idris Baker, National Clinical Lead for PEO LC

Idris updated the group on progress delivering the National Programme for PEO LC, emphasising that the National Programme is a catch-all term to describe everything that's being done developing national policy. The newly created National Programme Board (NPB), which will coordinate much of this work, will meet for the first time next month (November). Its remit covers all ages and complexities and the whole spectrum of end of life care services, including statutory and voluntary sectors, specialist and generalist, adults and paediatrics. The NPB also aims to include and be fundamentally guided by people's lived experiences and is putting in place mechanisms to do this.

The work of the National Programme is rooted in the principles of Value Based Healthcare with a strong focus on improving measures on population need, outcomes and costs of PEO LC. A new patient outcome measure is currently being developed which will better capture patient outcomes and inform data and service delivery. Work is also being carried out to improve population needs assessments which goes beyond a headcount to collecting more detailed data on what is needed by whom, when and where.

Idris updated members on the phase two funding review he is leading which is looking at models of care delivery across the full spectrum of palliative care. The phase two review builds on phase one which had a much narrower focus on funding for hospices. A key challenge of the phase two review has been its breadth and the limited availability of data to inform funding recommendations by the deadline of January 2023. For this reason, a phase three funding review is planned for next year to be completed by January 2024 and informed by more detailed population needs data. Phase two is now expected to have a focus on out of hours issues.

Prof Chris Jones, Deputy Chief Medical Officer

Chris said he and colleagues value the views of the CPG and are keen to work with it to improve PEO LC in Wales. He welcomed the work Idris is leading to do this, describing it as innovative and ambitious in its scope. However, he highlighted that the post pandemic difficulties facing health and social care, including the cost of living crisis and financial and workforce pressure, could impact this work and that lots of the processes surrounding the National Clinical Framework are under review at the moment.

Mark Isherwood thanked Idris and Chris for their updates and asked if anybody had questions.

Ceridwen Hughes said that she wasn't happy with the response the CPG received from Betsi Cadwaladr University Health Board (BCUHB) regarding out of hours provision and that she's heard nothing from them since she presented to the End of Life Board. She gave an example of a family she's supporting who had to call 6 times before getting through to out of hours one

evening and then they were told to go to A&E. She said the out of hours issue is wider than just BCUHB and needs to be addressed across Wales.

Idris Baker said he was sorry to hear these problems still persist and that he had talked to colleagues in BCUHB about the issues Ceri has raised. He agreed that things need to improve and that hopefully recommendations on out of hours in the funding review would help this. He also offered to help Ceri and others in addressing these issues.

Tash Wynne updated the CPG on research Marie Curie will soon be publishing on out of hours which will be looking at recommendations in Wales. She welcomed input from colleagues on this.

Chris Jones also offered help to resolve the issues Ceri raised if things can't be resolved through the normal channels.

Mark Isherwood said the CPG would work with Ceri to follow up on the issues raised.

Spotlight on impact of cost of living crisis on hospices in Wales

Trystan Pritchard, St David's Hospice

Trystan described how the cost of living crisis, combined with the impact of delayed referrals post Covid, is bringing added pressure to their services, including provision of respite and care at home. It is also weakening the ability and resilience of families to cope, increasing pressure on hospice services.

St David's is facing escalating costs for heating, food and the Agenda for Change uplift in wages meaning they have to find an additional £300,000 a year. This comes at a time when charitable fundraising is performing under budget due to cost of living pressures. To put this in context, 60-80% of Welsh hospices' income comes from charitable fundraising. Combined with escalating costs, this means St David's is looking at a net impact of over half a million pounds.

Trystan said that this is the worst situation he's experienced in ten years and that hospices will need support from Government to carry on delivering services.

Andy Goldsmith, Ty Gobaith Children's Hospice

Andy said he was speaking in place of Tracy from Ty Hafan and highlighted that their energy costs have increased three fold to £600,000. For Ty Gobaith staffing costs and recruitment are a huge issue with very high vacancy rates for paediatric nurses (18-25% vacancy rate) and hospices struggling to compete with the NHS. He described a cost base increase of 25% for children's hospices.

Andy described a perfect storm of increased demand, increasing hospice costs and reduction in the resilience of families they support, with many struggling to access services due to travel costs etc.

Liz Booyse, City Hospice

Liz updated the group on a recent survey Hospices Cymru conducted with member hospices from across Wales. She said that hospices are still feeling the impacts of the pandemic and the cost of living crisis has compounded this. Key issues raised by members included:

- Huge increase in energy costs
- Significant challenges recruiting staff
- General increase in all running costs
- Impact on income generation
- Many hospices have stopped developing services and are now focused on core delivery
- Many hospices not prioritising building maintenance and repairs

Liz said that a good first step to help hospices through this difficult period would be to support them with the Agenda for Change salary uplift and possibly some targeted help through the next funding review.

Mark Isherwood recommended the CPG write to UK and Welsh Government highlighting the concerns raised and the options for Government to help.

Idris Baker said he was willing to help if he could and asked Trystan, Andy and Liz to send him relevant info.

Progress at Ty Gobaith children's hospice providing care in Cymraeg following work by the late Aled Roberts (former Welsh Language Commissioner)

Angharad Davies, Head of Care at Ty Gobaith Children's Hospice

Angharad presented the Tŷ Gobaith Cynnig Cymraeg/Welsh Offer to the CPG describing the fantastic services they offer in Welsh through their North Wales hospice. She outlined the five key aspects of the Welsh offer:

1. We understand how important it is to receive care in your first language – that is why we ask families their language preference and strive to provide nurses and carers who speak Welsh to those families who ask for it
2. We have Welsh website available with a language choice button
3. We are very proud that we have a number of staff with Welsh language skills and we encourage staff to show the public who speaks Welsh with Iaith Gwaith resources
4. Every member of staff answers the phone bilingually, and if the staff member does not speak Welsh, they offer to transfer the call to a Welsh speaker when possible

5. We provide Welsh communication to our supporters when possible. Ask for Welsh communication to receive thank you letters, newsletters, posters, presentations and fundraising support in Welsh

Angharad also shared a video with members: [Cynnig Cymraeg | Hope House Children's Hospices](#)

Mark Isherwood thanked Angharad and commended Ty Gobaith on it's amazing work. He asked how use of Cymraeg could be supported more in hospices.

Angaharad said the best way to promote the use of Welsh was to first encourage and support existing Welsh speakers working and volunteering for the hospice and create a positive environment for the language to be used more.

Update on CPG inquiry report into experiences of palliative and end of life care in the community during the pandemic

Matthew Brindley, CPG Secretary

Matthew provided CPG members with a brief update on the initial key findings and recommendations from the inquiry report.

Key findings:

1. PEOLC played a critical role in the pandemic response and many in health and social care worked tirelessly at significant personal risk to support people at end of life
2. However, we weren't well prepared for the massive increases in demand for PEOLC care in the community
3. Many people had difficulty accessing end of life care at home and in care homes leading to devastating experiences
4. Visiting restrictions in care homes and other settings caused untold pain and distress
5. There was a revolution in collaboration, innovation and creative working across health and social care

Recommendations:

- Learn from the pandemic and build on good practice
- Pivot capacity into the community
- Make palliative and end of life care everybody's business

Mark Isherwood highlighted the need for the report to include a focus on the impact on care workers during the pandemic, based upon the evidence heard from Care Forum Wales, Care Home Staff and others involved in the inquiry.

Idris Baker welcomed the focus on future planning for pandemics and the critical role PEOLC played in the response.

Ongoing issues/updates

Mark Isherwood asked members if they had any priorities they wanted the CPG to focus on in future meetings. Mark suggested the group should look at reviewing bereavement support funding and the relationship between hospices and health boards.

Andy Goldsmith suggested the CPG look at local authority provision of short breaks for children with life limiting conditions.

Andy also asked if they could still input into the funding review. Idris said they could and they would be happy to have a conversation on this.

Date for next meeting is 20th January 2023 @ 3pm on Zoom