

GTB Hosbisau a Gofal Lliniarol 23 Medi 2020, 8:30-9:30

CPG Hospices and Palliative Care 23 September 2020, 8:30-9:30

AGM and Compassionate Cymru through Covid-19 (held over Zoom)

Cofnodion | Minutes

Yn bresennol | Attendance

Mark Isherwood MS, (Chair)	Jennifer Ramsay, representing Paul Davies MS
Dr Dai Lloyd MS	Leo Holmes, representing Jeremy Miles MS
Rhun ap Iorwerth MS	Heledd Roberts, representing Rhun ap Iorwerth MS
	Ryland Doyle, representing Mike Hedges MS

Anne O'Regan, ACE	Kate Williams,
Bethan Edwards, BHF Cymru	Kim, ACE
Catrin Edwards, Hospice UK (Secretary)	Laura Hugman, Paul Sartori Hospice at Home
Ceridwen Hughes, Same but different	Lesley Bethell, Chair Compassionate Cymru
Dan Steer, Together for Short Lives	Lowri Griffiths, Marie Curie Cymru
Deborah Ho, Ty Hafan	Lynette Hartman, ACE
Dominic Carter, Hospice UK	Marika Hills, Macmillan Cymru
Elin Llyr, Deryn	Dr Mark Taubert, Palliative Medicine Consultant and Clinical Lead for AFCP
Emma Saysell, St Davids Hospice Care	Matt Greenough, Ty Hafan
Eunice, Coedpoeth Befrienders	Monica Reardon, Marie Curie
Grant Usmar, Hospice of the Valleys	Patricia Walters, Coedpoeth Befrienders
Hazel Cryer, ACE	Rini Jones
Iain Mitchell, St Kentigern Hospice	Sue Williams,
Jo Oliver, BHF Cymru	Tom Davies, Macmillan Cymru
Dr Julian Abel, Compassionate Communities UK	Tracy Jones, Ty Hafan
Dr Karen Pardy, SW Cardiff GP Cluster	Tracy Livingstone, Nightingale House Hospice
	Trystan Pritchard, St Davids Hospice

Ymddiheuriadau | Apologies

Angela Burns MS	Helen Mary Jones MS
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Jayne Bryant MS	Llyr Gruffydd MS
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Croeso | Welcome

The Chair opened the meeting and welcomed attendees to the second virtual CPG Hospices and Palliative Care, serving as the AGM. The meeting brought the CPG back towards its planned work of considering the role of Compassionate Cymru with this meeting looking at Compassionate Cymru through Covid-19. Video visits to compassionate communities projects served to bring the CPG as close as possible to the site visits planned prior to the pandemic. These videos are available on the [CPG's Youtube playlist](#), hosted by Hospice UK.

Dyddiadur digidol | Video diary

Compassionate Coedpoeth in action

<https://www.youtube.com/watch?v=OdrLZ6Wa3zU&list=PLmKts5pTz0WwW8Bhrys-FAMLdWv9W4WdM&index=2>

Pat Walters, part of the Coedpoeth Befrienders, responded following the video to outline that the client in the film had dementia and the befriending was a form of support to him and to his carer-wife. The movement is very much concerned with building relationships and support for the whole family.

Tracy Livingstone noted that the model of Compassionate Communities in North East Wales is supported by Nightingale House Hospice through induction training and other support but that the community groups are independent and self-monitoring.

CCB | AGM

Mark Isherwood MS stepped down as Chair.

Rhun ap Iorwerth MS nominated Mark Isherwood to be re-elected to Chair. Seconded by Dr Dai Lloyd MS and Jenny Ramsay on behalf of Paul Davies MS.

Mark Isherwood was duly elected as Chair of the CPG Hospices and Palliative Care for 2020/21.

Catrin Edwards stepped down as Secretary.

Dai Lloyd MS nominated Catrin Edwards on behalf of Hospice UK to provide Secretariat. Seconded by Rhun ap Iorwerth, Mark Isherwood and Jenny Ramsay on behalf of Paul Davies MS.

Catrin Edwards elected as Secretary.

Cofnodion y cyfarfod diwethaf | Minutes of the last meeting

Tom Davies confirmed the minutes were an accurate reflection of the meeting.

Update on actions:

- Update on hospice emergency funding. Expect the current arrangement to be extended to March 2021, maintaining the original limit of £6.3m. Diarised meetings between hospices and the End of Life Care Board every other month.
- CPG Hospices and Palliative Care will be meeting jointly with CPG Funerals and Bereavement on 10 November, 6pm. Bereavement in the wake of Covid will be on the agenda.
- Note: Health, Social Care and Sport Committee first report on covid response, including the supply of PPE to hospices.

Taith tywys rhithiol | Virtual tour

Cardiff South West GP Cluster

<https://www.youtube.com/watch?v=-AAtt66AnAE&list=PLmKts5pTz0WwW8Bhrys-FAMldWv9W4WdM&index=1&t=1s>

Dr Karen Pardy reflected that the short video was only a snapshot of a large project. A longer version of the video will be made available on the Youtube channel.

Hazel Cryer explained how the community development work is about helping people to solve their own problems, including problems that GPs wouldn't be able to address.

Hazel noted that it would be helpful to be linked in with other organisations doing similar work.

Covid tosturiol? | Compassionate Covid?

Dr Julian Abel and Dr Mark Taubert presentation – slides




Creating a compassionate country


- National steering group made up from political support, business leaders, educational leaders, religious leaders, media, unions, health and social care leaders, and environmental leaders.
- Local steering committees made up from local equivalent leaders.
- Local committees focus around a work programme of implementing the Compassionate Cymru charter and feed into the national committee to report progress.
- Community development workers are the key people who will instigate projects on the ground

Benefits of Compassionate Cymru

- Become the first country in the world to become a compassionate country and become an international example
- Compassionate organisations, education, religious bodies, civic structures, media, museums and galleries etc
- Build the resilience of communities from the ground up, using a whole community approach
- Recognise the proud history of strong Welsh communities
- Increase social cohesion, decrease loneliness and increase the health and wellbeing of the nation.



What is needed

- 2 community development workers for a 3 year period
 - Administration support
 - Support of Compassionate Communities UK – world leaders in compassionate communities
 - Look for future resource from non governmental sources during first 3 years
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Mark noted that key to compassionate communities approaches is the communication of knowledge and connections.

The potential of digital is significant: devices have been used to connect people in hospitals to their families and to engage in spiritual support.

Lesley Bethell informed the Group that there were three posts in development/being recruited to as part of delivering Compassionate Cymru. Marika Hills noted that financial and development support for these posts is provided by Macmillan.

Mark Isherwood noted that this approach ties in with asset-based community development, led from the ground up.

MI asked whether there is now greater openness to talking about death and dying.

JA stated that we need to change the nature of Advance and Future Care Planning conversations from place of death to 'what matters', to enable people to live well to the end.

JA noted that Covid-19 had seen more than 1 million people sign up to volunteer across the UK and the establishment of 4,000 mutual aid groups.

People should be seen as 'citizens' first, rather than volunteers.

We need a system that recognises the importance of social connections, not just health care.

Compassionate Communities UK, along with RCGP and other groups, have submitted a response to the Health and Social Care Select Committee inquiry in Westminster noting the role of communities to the Covid-19 response.

Action: This response to be share with the group for interest.

Patricia Williams noted that it is important to capture activity that is already happening in communities, and the importance of supporting volunteers in this venture.

Janette Bourne noted that Cruse Bereavement have seen an increase in demand for bereavement care. The relational approach JA refers to is already alive in Wales and supports

signposting people to appropriate support. Dr Idris Baker has been tasked with establishing a Steering Group to drive forward a national bereavement framework for Wales.

MI asked where there was one standout lesson from the Covid-19 period for Compassionate Cymru to take forward.

JA noted the importance of maintaining volunteer interest and the role of social relationships in rebuilding.

MT recommended that death and dying are not over-medicalised, despite his professional background as a Palliative Medicine Consultant. Communities are important and it should not be seen as unusual to die at home or to connect with a dying relative remotely when families can't attend in person.

Tracy Livingstone noted that Compassionate Communities must be about meeting the communities specific needs.

Dyddiadur digidol | Video diary

Compassionate Pembrokeshire in action

Luke Conlon joined the group in person to talk through the approach in Pembrokeshire.

Prior to Covid-19 embarked on a year long project in the South Pembrokeshire District Hospital and in two care homes to support Advance Care Planning conversations and to provide care and company to people to ensure no one dies alone. The annual budget was around £10k, which is small, but this was supplemented with significant time and energy.

During Covid-19, the three workers spent four months as Health Care Assistants in the hospital to support people dying alone and to provide companionship that other clinical staff do not always have the capacity to give.

Since Covid, embarking on socially distanced activities, such as a Good Grief beach walk and an online bread making course for men caring for their dying relatives.

Compassion is not a competition; Wales should become a compassionate nation but does not need to be the first.

Video diary:

<https://www.youtube.com/watch?v=aBqJPnZhbEA&list=PLmKts5pTz0WwW8Bhrys-FAMldWv9W4WdM&index=3>

MI raised previous comments around whether Compassionate Cymru should be about death and dying or about the wider system.

JA stated that a whole community approach improves outcomes across the wider health and care system. Health and wellbeing comes through social relationships as well as traditional health care.

PW noted that support for people affected by death and dying is not mutually exclusive from wider community support.

MI noted that hospices should not be delivering the whole of Compassionate Communities but should play a role in supporting others to do so. Health Boards and Local Authorities must be tasked with taking on more of this agenda.

Diwerddariadau arwyddocaol | Significant updates

- £500 carer bonus: Hospice staff working in Hospice at Home services regulated by CIW as domiciliary care providers may be eligible for the £500 social care worker bonus. This is in comparison with staff, such as Health Care Support Assistants, working in other hospice settings, who would not be eligible.
- Hospice Care Week 5-11 October – theme this year is again 'This is what it takes'.

UFA | AOB

Ceridwen Hughes shared in the chatbox her experience of caring for her mother as she died at home during lockdown. Her family experienced significant difficulties in accessing support for their mother, particularly with regard to pain management in the three weeks leading to her death. Having being diagnosed with terminal cancer and stating that she wished to die at home the family were given very little information in how to prepare for her death. Ceridwen's sister is a nurse and was happy to care for her mother at home, however, despite her medical experience nothing prepared her for the difficulties they faced. Covid made the whole experience more difficult, as their GP refused to visit their mother at home, and the family did not feel listened too with regard to their difficulties accessing pain medicines that worked in this situation. Ceridwen filmed an interview with her sister during the period of caring for her mother, which includes footage of her mother in pain. The family is eager to share their experience in the hope of highlighting the need for a more joined up approach for families when their loved one chooses to die at home rather than a medical setting. The family are happy for this video to be made available to the group. If members of the Group wish to see this video, it can be accessed at <https://www.youtube.com/watch?v=dfD4klURnE&feature=youtu.be> Please note, this video contains sensitive imagery of Ceridwen's mother in her last week of life.

The Group is grateful to Ceridwen for sharing her experience and wishes to convey its sincere condolences to her and her family.

If you would like to speak to Ceridwen about her experiences please contact her on Ceri@samebutdifferentcic.org.uk or on 07971 983028.

Action: Lesley Bethell to work with Ceridwen sensitively to present her experience to the End of Life Care Board.

Cyfarfodydd nesaf | Next meetings

10 November 2020 6-7:30pm, joint meeting with the CPG Funerals and Bereavement

20 January 2021 8:30-9:30