

GTB Hosbisau a Gofal Lliniarol 4 Mawrth 2021 12-13:30

CPG Hospices and Palliative Care 4 March 2021 12-13:30

Coproducing recommendations to conclude our inquiry:

What role can the Welsh Government's Compassionate Cymru programme play in building capacity and resilience in communities through and beyond Covid-19?

Cofnodion | Minutes

Yn bresennol | Attendance

Mark Isherwood MS, (Chair)	Rhun ap Iorwerth MS
Darren Millar MS	

Andy Goldsmith, Ty Gobaith	Jonathan Ellis, Hospice UK
Carys Stevens, Law yn llaw, HDdUHB	Julian Abel, Compassionate Communities UK
Catrin Edwards, Hospice UK (Secretary)	Kimberly Jones, Macmillan/ACE
Chris Campbell, Thornhill Community Centre	Laura Hugman, Paul Sartori Hospice at Home
Dan Steer, Together for Short Lives	Lesley Bethell, Chair Compassionate Cymru
Dominic Carter, Hospice UK	Liz Andrews, City Hospice
Donna Humphrey, Shalom House	Lowri Griffiths, Marie Curie Cymru
Emily Harrop, MCRC, Cardiff University	Marika Hills, Macmillan
Emma Saysell, St Davids Hospice Care	Melanie Minty, Care Forum Wales
Fiona McDonald, MS Society	Monica Reardon, Marie Curie
Grant Usmar, Hospice of the Valleys	Pat Walters, Coedpoeth Befrienders
Helen Davies, Bracken Trust	Rahila Hamid, EYST
Iain Mitchell, St Kentigern Hospice	Rini Jones, Hospice UK
Dr Idris Baker, National Clinical Lead	Shabir Hussain, Newport City Council
Janette Bourne, Cruse Bereavement	Tom Davies, Macmillan Cymru
John Moss, Welsh Government	Tracy Jones, Ty Hafan

Ymddiheuriadau | Apologies

Dr Dai Lloyd MS	Andrea Williams, Covid-19 Families Wales
Professor Uzo Iwobi, RCC	

Croeso, cofnodion y cyfarfod diwethaf a diweddariadau arwyddocaol | Welcome, minutes from the previous meeting and significant updates

Minutes from the CPG Hospices and Palliative Care meeting on 20 January 2021 were confirmed as an accurate reflection of the meeting.

- Debate on palliative and bereavement care through the pandemic was held on 3 February and led by Mark Isherwood MS. In his response to the debate, the Minister announced an additional £3m to support hospices during this financial year. A written statement from the Minister is expected shortly.
- Chair wrote to the Chair of the National Bereavement Steering Group highlighting the evidence received by the CPG from BAME community leaders regarding the inaccessibility of bereavement support for people from BAME communities. A constructive response was received outlining the inclusion of BAME community needs within the National Bereavement Framework.
- Debate on children's hospices, led by Mark Isherwood MS, to be held in Plenary on 24 March.

Trafodaeth banel ar argymhellion ddrafft y GTB | Panel discussion on CPG draft recommendations

- **Monica Reardon**, Marie Curie, Rheolydd Prosiect, Gwasanaethau Gofal | [Project Manager, Caring Services](#)
- **Dr Idris Baker**, Cadeirydd Grwp Llywio Gofal Profedigaeth a Arweinydd Clinigol Cenedlaethol | [Chair of the National Bereavement Steering Group and National Clinical Lead](#)
- **Andy Goldsmith**, Prif Weithredwr | [CEO Ty Gobaith/Hope House](#)
- **Lesley Bethell**, Cadeirydd Cymru Garedig | [Chair of Compassionate Cymru](#)

A1: Ymgysylltu â a chefnogi cymunedau wedi'u hilio

- Dylai cymunedau BAME fod yn cydgynhyrchu mentrau Cymunedau Caredig o'r chychwyn cyntaf
- Dylai gwasanaethau ffurfiol ymgysylltu'n rhagweithiol â'r cymunedau BAME y maent yn eu gwasanaethu

"We are an add on"

Professor Hadassah Radway, BHM Cymru

R1: Engaging and supporting racialized communities

- BAME communities should be involved from the outset in coproducing Compassionate Communities initiatives
- Formal services should proactively engage with the BAME communities they serve

Monica Reardon (MR) welcomed the inclusion of diverse voices in the inquiry to date. Compassionate Cymru should take a strength-based approach by starting where the community is and building on the work that's already ongoing.

Idris Baker (JIB) noted that for every person who has died, we anticipate five people will be bereaved. Bereavements during the pandemic are likely to lead to more complex grief responses. The National Bereavement Steering Group has heard how people from some ethnic communities have not always felt they are able to access support. Access for BAME people to appropriate bereavement support will form part of the National Bereavement Framework.

Andy Goldsmith (AG) noted that if we only consider people at the end of life in this context then children with life-limiting conditions and their families will not always be included. There is a higher prevalence of life-limiting conditions among children from BAME backgrounds, particularly South Asian ethnic backgrounds, however these children and families are under-represented in children's hospice services. We need to understand the barriers these families face and break them down.

Lesley Bethell (LB) advocated for a Compassionate Cymru programme that builds from the bottom up, as well as from the top down. While this is not always easy, LB agreed that an asset-based approach should be the way forward. This involves making sustainable connections with people and communities.

Mark Isherwood (MI) referred to Cruse's approach to invite volunteers from diverse communities to join their team.

Marika Hills (MH) raised the role of Macmillan in facilitating and funding the Compassionate Cymru workforce.

Chris Campbell (CC) noted that the implementation of the recommendations is key. While the bottom-up approach is essential, the 'middle group' of local and regional planners and leaders must take on and understand the approach to connect the community action and the national steer.

MI: By 'asset-based' we're really talking about people. People can drive the cultural change needed.

MR: Formal services that engage with communities must listen and commit to making changes.

A2: Ei gwneud hi'n fusnes i bawb ofalu cyn marwolaeth ddisgwyliedig a thrwy profedigaeth

- Blaenoriaethu anghenion profedigaeth yn dilyn Covid-19
- Cysylltiadau cymunedol ehangach
- Gwellu mynediad at ofal cyn-brofedigaeth
- Hyrwyddo'r angen am fynediad agored at wasanaethau profedigaeth

R2: Making it everybody's business to care before an expected death and into bereavement

- Prioritise bereavement needs following Covid-19
- Wider community links
- Improve access to pre-bereavement care
- Promote the need for open access bereavement services



JIB: Bereavement care professionals will continue to be responsible for care but we should acknowledge that a significant amount of 'bereavement care' is not formally recognised as such. This is because communities are effected by bereavement and communities respond. During the pandemic, more people are experiencing multiple factors that lead to complex grief, including guilt and isolation. Pre-bereavement care, for the person and their family, can improve bereavement outcomes. We should recognise having good end of life care as a 'pre-bereavement' experience as it is known to affect loved ones' grief outcomes.

MR: this recommendation should explicitly reference the role of community leaders from diverse communities.

AG: Welcomed the reference to pre-bereavement, which should extend to sibling support. Children's hospices take an asset-based approach. Support is 'family-centred', which means we offer bespoke support based on the individual family's needs. This might be help with homework or other practical tasks. Families often report feeling invisible within their communities and the death of a child is still largely taboo. However, communities can provide valuable support for families.

LB: Pre-bereavement support is more important now than ever given that families, carers and dying people have spent 80-90% of the past six months not with professionals. There is often a stigma associated with being helped. We need to mobilise people to do the ordinary things.

Julian Abel (JA): We think of bereavement as a service but that's not always the case. The RCGP is considering community-led support to respond to the increase in bereavement needs following the pandemic. Using a population-based approach is essential.

- Catrin to circulate the RCGP document.

JIB: The draft bereavement framework has these principles underpinning it but JIB questions whether this has been captured explicitly.

A3. Gofalu am deuluoedd a gofalwyr

- Cefnogaeth rithwir a wyneb-i-wyneb (Covid-diogel)
- Mynd i'r afael â bylchau yn y gefnogaeth i deuluoedd â phlant â bywyd cyfyngedig

R3. Caring for families and carers

- Blend virtual and in-person (Covid-safe) support
- Address gaps in support for families with life-limited children



AG: There are around 3,500 children with life-limiting conditions in Wales, of these 800 need active palliative care. The impact of caring for a child with a LLC is significant and some children will experience several end of life episodes. We should reflect on the social experience of providing care. Families provide 95% of their child's care. Challenges associated with this have been exacerbated by Covid-19 – schools have closed, children's wards have been repurposed and hospices were temporarily closed for planned respite. Covid has taught us we can do virtual but it's a pastiche for face to face care. Care also needs to be for the whole family. Planned respite is an essential service for families.

MR: We should not make assumptions about how much care is or will be given by families, particularly for carers from minority ethnic backgrounds. We need to focus on supporting people to recognise themselves as carers.

LB: Again, this is related to the stigma about asking for help. We must listen to people.

MI: Covid has exacerbated distance from families and our ability to draw on community support.

JIB: We should not be making assumptions about carers – that amounts to a failure to listen to them. In the past, health professionals may have considered families visiting in hospitals as crowding but the past year has taught hospital staff about the value of families and carers and the particular roles they fulfil in supporting people being cared for.

MI: There is a parallel here around the role of carers and visitors to people in care homes.

A4. Arwain sgwrs genedlaethol am 'yr hyn sy'n bwysig' ar ddiwedd oes

R4. Leading a national conversation about 'what matters' at end of life

'Don't over-medicalise death.'

Prof. Mark Taubert

- Model cymdeithasol o gynllunio ar gyfer diwedd oes.
- Cysylltu pobl â phrofiad o gynnal sgwrsiau 'yr hyn sy'n bwysig' i gynorthwyo pobl nad ydynt yn weithwyr proffesiynol i ymgysylltu â chymunedau ehangach
- Social model approach to planning for end of life.
- Connect people with experience conducting what matters conversations to support non-professionals to engage wider communities

LB: 'What matters' conversations are sometimes referred to as 'shared decision making'. These should not be one-off events but ongoing and changing, and this should be reflected in any formal Advance Care Plans. We all have a role in conducting these conversations, not just specialists. Only a small proportion of these conversations will be conducted with experts; most will happen between families or carers. While we all have a role in this, dying is not something we all know much about. Families also don't always know how to take forward actions. It can be difficult to make promises to dying people about fulfilling their wishes because we can't guarantee that the support they need will always be available, or will be suitable for them.

MR: Agree with the social model approach, including working with non-professionals.

AG: Conversations about death and dying are, and should be, social as much as medical. It can be scary for families and it takes confidence to ask for support. It's also not cheap or free to support people; it requires investment to provide support. Covid has seen greater numbers of volunteers and there's an opportunity to capitalise. This is the time to act.

JIB: The responsibility for conducting what matters conversations lies with 'both/and', rather than 'either/or', professionals and communities. Professionals need communities as part of this approach to planning our end of life care.

Trafodaeth agored | Open discussion

MI opened the discussion on the relevance of Compassionate Communities approaches and the Compassionate Cymru programme beyond the scope of end of life care. Other relevant approaches that should come under this umbrella include dementia friendly communities, autism friendly approaches.

LB agreed that this is an approach that should be open to, and benefit, everyone. This is about social connections and supporting communities to connect.

JA noted that this approach extends way beyond the end of life care sector. It takes a public health methodology and there is an opportunity in Wales to involve every sphere of life in this approach.

AG noted the relationship between quality of life and quality of death.

Carys Stevens: What matters conversations are the basis for the Law yn Llaw project in Ceredigion. Volunteers, even virtually as through the pandemic, bring a richness to people in hospital wards. What matters to some people can be a volunteer facilitating a person in hospital seeing their dog virtually, for example.

MI noted that many politicians will receive messages of concern regarding 'what matters' conversations in relation to the Social Services and Wellbeing Act.

IM: Hospices support 'all community' – we don't compartmentalise. Signposting for bereavement care is up 40%

MI closed the discussion on the draft recommendations by noting the next steps:

- Refining the recommendations]
- Sharing a short report with contributors and the Welsh Government by the end of March 2021

Myfyrio ar y GTB yn ystod y 5ed Senedd | Reflecting on the CPG during the 5th Senedd

The Chair noted that the CPG would formally close as the Senedd enters the pre-election period at the end of March 2021.

Catrin Edwards put on record thanks from Hospice UK, Hospices Cymru and colleagues with an interest in hospice and palliative care, to Mark Isherwood MS for his continued support and significant work in chairing the CPG and championing the cause in the Senedd.

MI suggested the CPG should compile a Legacy Report to inform future work in the coming Senedd term.

- Catrin to draft Legacy Report.

Unrhyw fusnes arall | Any other business

- Lowri Griffiths, Marie Curie Cymru, informed the group of the National Day of Reflection campaign, which will be held on the anniversary of the national lockdown on 23 March 2021.
 - CE to circulate National Day of Reflection materials to attendees.