

GTB Gofal Hosbis a Lliniarol, 19 Mai 2022, 14.30-15.30

CPG Hospice and Palliative Care, 19 May 2022, 14.30-15.30

Cofnodion | Minutes

Experiences of end of life during the pandemic

Evidence session 4: Impact on workforce health and wellbeing

Yn bresennol | Attendance

Mark Isherwood MS	Altat Hussain MS
Rhun ap Iorwerth MS (rep Heledd Roberts)	Mike Hedges MS (rep Ryland Doyle)
Jane Dodds MS (rep Rhys Taylor)	

Lewis Clark, Tŷ Hafan & Tŷ Gobaith	Bethan Edwards, Marie Curie
Liv Warnes, Hospice UK	Eleri Cubbage (MS researcher)
Millie Jenkins, MND Association	Liz Andrews, City Hospice
Melanie Minty, Care Forum Wales	Laura Hugman, Paul Sartori Foundation
Tracy Jones, Tŷ Hafan	Anna Tee, Macmillan Cancer Support
Emma Saysell, St David's Hospice Care	Gethin Rhys, Cytun
Janette Bourne, Cruse	Kim Jones, Hospice of the Valleys
Jane McGrath, St Kentigern Hospice	Idris Baker, National Clinical Lead EOLC
Tom Davies, Macmillan Cancer Support	Professor Jonathan Bisson, Canopi
Trystan Pritchard, St David's Hospice	John Moss, Compassionate Cymru
Emma Priest, Hospice of the Valleys	Lisa Griffiths, Pen-Y-Bont Care Home

Ymddiheuriadau | Apologies

Grant Usmar, Hospice of the Valleys	Llyr Gruffydd MS
Peredur Owen Griffiths MS	Iain Mitchell, St Kentigern Hospice
Matthew Brindley, Hospice UK	

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

Mark Isherwood MS opened the meeting and welcomed everybody. Minutes from the previous meeting were proposed as a true and accurate record by Gethin Rhys and seconded by Lewis Clark.

Mark Isherwood MS updated members on progress against actions since the last meeting. The CPG wrote to the Chair of the UK Covid-19 Inquiry and Welsh Government Minister for Health and Social Services asking for deaths at home to be included in the terms of reference for the inquiry. Eluned Morgan responded, confirming the First Minister would raise the issue in his response to the consultation. The

Inquiry Chair, Baroness Hallett, also replied confirming they would consider our request alongside that of Hospice UK and others.

Baroness Hallett has now published her recommended terms of reference which are now with the Prime Minister. They include specific reference to 'care in the home, including by unpaid carers' in the section on the management of the pandemic in certain settings. Baroness Hallett also confirmed that deaths in private homes will be covered under a broader examination of the consequences of the pandemic on non-COVID related conditions and needs. This is good news, but further collaborative work will be needed to ensure deaths at home are properly addressed when the public inquiry is up and running.

At our last meeting we agreed to invite the Association of Directors of Social Services and/or a representative from the WLGA to attend a future CPG session to talk about family access to respite. Now the local elections are over I suggest we include this at our next meeting in July.

Ongoing and arising actions

Date	Action	Status
17 th March	CPG to write to UK Covid 19 Inquiry Chair, Baroness Hallett and Health Minister, Eluned Morgan about including deaths at home in terms of reference for inquiry	Complete
17 th March	Invite Association of Directors of Social Services and/or a representative from the WLGA to attend a future CPG session to talk about family access to respite	Pending

Experiences of end of life care during the pandemic: Impact on workforce health and wellbeing

Experiences of hospice staff

Mark welcomed Kim Jones and Emma Priest from Hospice of the Valleys and Laura Hugman from Paul Sartori to talk about providing hospice care in the community throughout the pandemic and how this affected them, their families and their colleagues.

Kim Jones, Deputy Head of Clinical Services at Hospice of the Valleys:

- My experience is in regards to staff and how we struggled through Covid. A big part of that was to do with many of my team being quite young and having young children. One of the difficulties we faced was to do with childcare; trying to maintain our service while looking after children.
- My husband's a GP and I have a clinical role so my ten year old was able to go to a hub school, but for the majority of my team they weren't able to access a place.
- A lot of the stress over Covid for my team wasn't so much about the worry of being in contact with people with Covid, but more the practicalities of managing your day-to-day work. People were working late into the evening and those of us working from home were wishing we could be at work and those of us at work were wishing we could be at home; there was no happy medium and it was really challenging.
- For me it was the guilt of dropping my son off and leaving him when the rest of his class were all at home, and the guilt of not being able to work my normal hours, and I found that very difficult.
- For the team it did cause a little bit of conflict, for those who didn't have children perceiving that the others in the team could leave early and work from home.
- It was a really trying time and we've come through it but it was very challenging and I think it was those feelings of guilt for not being able to fully meet the needs of our children and families and the services we provided for people.

- We found having regular virtual meetings and supporting each other really important, and I have to say cake played a big part.

Emma Priest, Advanced Nurse Practitioner, Hospice of the Valleys:

- I've got a team in the hospice and a team of registered nurses up in the hospital and nothing really prepared me throughout my training and over the years for what happened with Covid.
- Throughout the first wave of the pandemic morale was quite high and despite there being an undercurrent of fear we all pulled together in the hospital, however, as the second wave came on, it became more trying and people became more exhausted and emotionally distressed.
- My patients were admitted into hospital with mild symptoms and declined rapidly and died really quickly and I was really taken aback by that.
- And people were very quick to say you're a palliative nurse, you deal with dying all the time, but this was nothing like I'd ever prepared for or seen before.
- I'd never imagined myself saying that families couldn't visit their relatives and that they may have to die alone, I'd never imagined that.
- I had a patient with dementia admitted for a fall, and she was medically fit for discharge but couldn't be discharged, she didn't understand what was going on and was isolated in a single room and she contracted Covid. She held my hand and looked me in the eye and told me she wanted to go home and I couldn't facilitate that. That will stick with me forever.
- That was just the tip of the iceberg, there were a lot of other incidences that our team in the hospice blanked out, these people were dying on their own and we blanked a lot of that out for wellbeing really.
- It was exacerbated by the fact that we went home, we worked and we went back home and we couldn't go anywhere else with colleagues to come to terms with things and that's carrying on now.
- I'm really honoured to work for a hospice and to be able to come from the ward and debrief with my team here, others weren't able to do that so I was like their shoulder to lean on and cry on upon on the ward. But not only do I have to deal with my emotional stress but also others as well and that has had a lasting affect and I think it will take a while for that to resolve.
- It's about supporting people and that's it.

Laura Hugman, Clinical Team Manager, Paul Sartori Hospice at Home:

- Working through the Covid Pandemic was like standing on the shore with a battered Peppa Pig umbrella, waiting for the Tsunami to hit.
- Then it was like being on a rollercoaster with no seatbelt or safety harness, for 2 years!
- Not surprisingly no-one in the team volunteered to join me today, it's like no one wants to talk about it anymore.
- I did put everyone on the spot in our team meeting on Monday. I asked for 2 words or sentences to describe how they found working in the Pandemic.
- The words that came up were frightened, scared, harrowing, freaked out, vulnerable, angry, frustrated, resentment, constant change, constant adjustment and constant anxiety.
- I remember a day in March 2020 when cases were rising, other organisations locally were closing their doors and I was left feeling very isolated with a Clinical team of 45 people to look after, who needed to provide essential end of life care for patients in their own homes. There was a pressure for Paul Sartori to continue. There was a massive lack of PPE. The community needed us. I felt a massive burden of responsibility sending the team to the frontline with minimal protection as any PPE we had was running out.
- As a senior team and trustees we met, I advised the trustees we either needed to suspend services or we needed to buy PPE to keep the team safe.
- That day PSF paid £3,000 for 1,000 masks. We made the decision to carry on. We put the call out to our community links. We were overwhelmed with offers of PPE people had for other purposes, e.g. vets, beauticians. It was never hundreds, it was a few packets here and there from

many sources. Mechanics donated car seat covers, hundreds of scrubs were sewn together from bedding donated to our retail stores by our volunteer army. Visors were made at the local college. We were quickly able to offer every team member a PPE box, with everything they needed to feel a bit safer.

- Then we had the testing, uncomfortable gagging every week, then every day, to carry on providing care with constant worry about bringing the virus home to our own families. We had the relief of the vaccinations, optimistic this would provide a level of protection. We were envious of colleagues who had been furloughed or who were required to isolate as this gave them an authorised break from the intensity of work.
- We missed hospital/care home visits for our loved ones and deaths of loved ones. We missed funerals, births of grandchildren. Our family members were working in health care too, 1 experiencing 9 deaths in 1 day. This is too painful for them to even talk about. We struggled to home school our children, or we sent them to unknown hub schools, with a few other 'key worker' children, not with their friends, not to be taught but to be cared for in the school setting. The sense of guilt was immense and we saw this provoke anxiety in our children. We couldn't answer their questions. There were no answers. There were no answers for anyone.
- But we carried on, month after month, adapting to the new normal, constant change. No one thought it would last that long. We thought working from home would be just for a few weeks, then until the end of summer then until Christmas, then we stopped asking, resigned to the new normal and the unknown.
- The PPE provided a level of reassurance and protection but really scared our patients, particularly the elderly and frail and those with Dementia, struggling to make sense of day to day life. We looked like Beekeepers. They couldn't hear us, they couldn't see our compassionate and caring smiles. We adapted and we carried on. The team say they felt everything that could be done was done. They felt useful, working with a purpose, pleased and relieved to not be redeployed to an unknown field hospital or ward.
- The team work independently, day and night, assessing and providing day and night care. and respite. Before Covid, the team would visit the office and talk to colleagues about patients and families they had seen, they'd share the burden of responsibility and the sadness of each case. Covid meant there was no one to share this with. They took this home with them and this increased pressure and stress. They were still frightened and there were still no answers.
- The counselling team have received CPD on trauma and PTSD, they have said they have not cared for people who have been impacted this significantly by an external event before. There is trauma, a new complexity of referrals, again putting more stress on the team.
- There were no cakes to celebrate birthdays, no leaving do's, no get togethers in the staff room, no holidays, no shared coffee or lunch breaks, nothing to look forward to, no family or friends of their own to visit. We increased the number of phone calls to each other. We built capacity into our counselling service for our staff members, we offered remote complementary therapy products, we provided training sessions online and reflected together.
- The lessons to take forward are staff are bruised by Covid, tolerance, capacity and energy levels are low. There is a reluctance to talk about it but a need for recognition about what we've done. People need to feel valued and appreciated just as they did before Covid. As a team we are proud of what we have achieved over the past 2 years. Everyone who has worked through Covid has been on their own journey. Everyone is tired having worked at a heightened emotional level for 2 years. People still struggle to ask for help but there is a need to be kind and recognise warnings of burnout. If you are in a position to ask someone how they are, take the time to listen to their answer.
- People are re-assessing their priorities. Being flexible with Contracts may enable you to hang on to staff who want to leave and recruit new team members. Communication and consultation remains key to everything. If people do not feel valued and appreciated they will leave. They need to know you care.

Impact on care home staff

Melanie Minty, Care Forum Wales:

- We were starting from a very vulnerable base in health and social care when the pandemic hit. The role of care worker is very stressful, its demanding and it was always undervalued, even before Covid, so when Covid came along it made that even harder.
- There was additional workload because of Covid, people were having to do far more in depth cleaning and infection protection control procedures and when care homes were allowed to permit visiting again that was extra work that was falling on an ever dwindling number of staff because they had to self-isolate or had stress related illness.
- Many people were working to the point of exhaustion, they worked ridiculously long hours and didn't take any leave during the peak periods of Covid.
- There was so much self-sacrifice; it wasn't at all unusual for care workers to move into the care home to protect their families and the residents they were looking after.
- There were also relationship problems including domestic abuse; one of our care workers had a husband who wanted her to stop working and became quite violent when she refused.
- We also had people who worked part-time who increased their hours to support the workforce but the following month Universal Credit claimed the overpayment and they found they couldn't afford to buy food.
- It was dangerous. It was like a warzone. It was that bad at times. One of our members' had a nurse who died of Covid that she picked up in a home.
- There were at times when careers had to cope with a certain level of hostility from family members who couldn't understand why they weren't allowed to visit.
- One of our members said staff were regularly attacked by people with Zimmer frames and walking sticks when trying to carry out routine testing.
- It was a very alien and uncomfortable situation for people who work as carers.
- One of the worst things was having to make people isolate in their rooms and keep them apart; how do you do that with someone with dementia who is used to wondering?
- Social care workers felt that they were being sacrificed to the NHS because there was no PPE; when the clapping was happening for NHS heroes very few people mentioned social care.
- A lot of them who had emergency cards would go along to priority shopping slots and they would be turned away because the shop wouldn't recognise them; you're not a nurse.
- Sometimes there was a lack of support within the care home. Quite often the management would be off sick themselves so sometimes you would have care workers on minimum wage taking all this responsibility and having to make end of life decisions over the phone when GPs weren't coming in.
- Once Covid gets into a home it's impossible to stop it. One of our care home members lost 21 residents in two weeks.
- Care homes are not institutions, they are extended families, the residents and carers form relationships, so when you see your whole home falling apart before your eyes it's really traumatic. One of our members who ran a care home in North Wales did unfortunately commit suicide because he couldn't bear to see this happening to the people he loved so much.
- There is a lasting legacy from Covid, people are effectively suffering from PTSD, they are physically and mentally exhausted, we're seeing increasing numbers of people asking to change their hours and go part-time while a lot are choosing to leave the sector.
- Society is more or less getting back to normal, and staff in care homes can see that, but they're still having to make sacrifices, they're still having to do the testing, they're still having to wear PPE, they're still having to keep Covid out of the homes.
- I fear we're already starting to forget the sacrifices people have made and we need to keep reminding ourselves of the heroes they've been and make sure we don't attribute blame.
- We're really grateful for the increasing commitment WG are showing to the living wage, to some of the welfare and counselling services setup for social care workers.
- We need to remember they're just as important in social care as they are in health.

Lisa Griffiths, Head of Services & Responsible Individual, Pen-Y-Bont Care Home, Abertillery:

- Living and breathing Covid for the last two years has had a massive impact on my staff.
- Being the Responsible Individual in the home during the pandemic was the most difficult thing I've ever had to go through and it has scared me for life, but it's also scared other people.
- When people are coming to you for all the answers and you've got no answers to give them, it's really hard.
- People were coming in with make-up all down their face because they were crying before they even got through the door because they know what was ahead of them.
- When you're in a care home they become your extended family, so every day when you're losing people you were losing family members.
- The biggest thing for me was that my sister in law, who worked for me at the time in the home, contracted Covid and unfortunately passed away with it, so on top of all that I had to try and keep the morale up with the staff, giving them as much support as possible and be there every single day, having to face the loss of our residents as well as a staff member.
- I caught Covid myself and the guilt I had that I couldn't be there to direct them and be a shoulder to cry on. I remember being in my bedroom for 14 days and I didn't sleep working morning till night on phone to support my staff.
- Once the home caught Covid you were being scrutinized, there were lots of people calling you up asking where you've been, what you been doing, it was as if you'd have to go to prison for catching Covid, it was an awful experience for everybody.
- I believe a lot of people will have PTSD in the future when they think about what they lost.

Wider context and support for health and social care staff:

Professor Jonathan Bisson, Cardiff University and Director of Canopi mental health support service for NHS and social care staff:

- Canopi's predecessor organisation was called Help for Health Professionals Wales and that was set up in 2012 in recognition that a lot of Doctors felt uncomfortable about accessing mental health support through standard NHS services.
- In 2020, with the onset of the pandemic, WG were very supportive and agreed to expand this service to cover the whole of the NHS workforce so there was a rapid expansion of the service during 2020-21.
- In the eight years of its existence up until 2020 HHP saw about 600 people, but in the next year alone as an expanded service during the pandemic it saw 750 people working in the NHS.
- Canopi is a self-referral service where the individual will have a conversation for about half an hour with a trained practitioner, usually a GP, who will help identify what their needs are. They are then sign-posted to an appropriate level of support, ranging from self-help materials on websites, like the WG support Silver Cloud service, to informal peer support from colleagues in the NHS who have been trained up. For others we offer up to eight sessions of cognitive behavioural therapy with an accredited therapist.
- Just over 500 people have received face-to-face therapy, often over zoom, during the pandemic.
- From the 1st April this year we have been commissioned to support social care staff as well as NHS staff.
- Canopi is receiving about 30-35 self-referrals a week, around a quarter of which are from social care staff and we do expect this to increase over time.
- We are one service among many others provided for NHS and social care staff, including by individual providers and access to wider NHS services via your local GP.
- I'm surprised we didn't see more people presenting with PTSD directly related to their pandemic experiences, a more common presentation is one where the pandemic has affected an individual

presenting with anxiety and depressive symptoms, but you have to remember we are working with everyone in the NHS and social care.

- But for frontline workers PTSD has been more prominent.
- Other factors are very important, they include additional stresses like domestic issues, losing a job and income, childcare and schooling during the pandemic.

Open Discussion & Questions

Kim Jones from Hospice of the Valleys asked if the Canopi service was accessible to independent hospice and care home staff? Jonathan Bisson confirmed that it was and they would receive the same support as NHS and social care staff.

Liz Andrews thanked everyone for being so open and sincere in sharing their experiences over the last two years and that many of them resonated with her own experience.

Idris Baker echoed Liz in his thanks to the people who spoke and to the group, emphasising the importance that compelling testimony is heard in its own right and to be learned from.

Altaf Hussain thanked everybody for sharing what were often heart-breaking stories of real life challenges for nurses, care home and hospice staff. He asked if people thought the ethics and human rights of both patients and staff were maintained throughout the pandemic and how did the vaccination of patients affect the experiences people have shared?

Kim Jones said it was difficult to say people's Human Rights were maintained, because people should have had the right to see their family and were stopped:

It's difficult to say people's Human Rights were maintained, because people should have had the right to see their family and we stopped them didn't we? We looked after some of our most elderly and vulnerable people in society when time is often short and we limited the options they had to see their family, so on a personal level I'm not so sure their Human Rights were maintained, they didn't have that option, they didn't have that choice

Kim Jones said things were still pretty much the same after people were vaccinated, with visitors still not allowed and that it is only now that people are allowed to visit:

The time we lost we'll never get back and for patients who are now able to see their families but who suffer from a cognitive impairment they may no longer know who they are

Ongoing issues and updates

Dr Idris Baker, National Clinical Lead for palliative and end of life care provided an update on the EOLC quality statement, national programme and funding review:

- Still receiving feedback from hospices and others on the draft EOLC Quality Statement which is at quite an advanced stage. There has been delay due to the need for clarification on the purpose of the QS. Hoping to get final draft to the EOL Board in the next few weeks and there may need to be some internal WG steps to go through. Aim is to get a draft to the Minister and publish sometime this Summer.
- The National Programme Board for Palliative and End of Life Care will be initiated in July replacing the existing EOL Board. The work programme for the NP is under development and there is a steering group working on this.
- The phase one funding review for voluntary hospices was completed last year led by Veronica Snow who has made a colossal impact on the development of palliative and end of life care in

Wales over many years. On the back of that a phase two review is being carried out which has an ambitious remit, encompassing hospices and NHS palliative specialists as well as looking at the models of care and their funding across the whole spectrum of end of life care. Ambition is to report back by January 2023 and will be offering recommendations on models and funding and may include recommendations for further work to tackle the more difficult questions. Will keep CPG posted on review ahead of January deadline.

Altaf Hussain asked whether patients and their families have been involved both in their care and in developing the draft policies? Idris Baker confirmed that communication with a patient and their family is at the heart of individual care, but where this could be improved is in the development of policy and services.

Lewis Clarke asked how much engagement will be involved in the phase two funding review considering there was quite a lot in the phase one process.

Idris said there will be some engagement, but they need to get the balance right due to the tight timescale. They don't want to redo all the engagement that's already been done for phase one and the stocktake report, but are planning selective engagement with a wide range of services, not just specialist palliative care. He said they are very happy to hear from anyone.

Liv Warnes from Hospice UK provided an update on the CPG callout for written evidence on EOLC experiences during the pandemic on behalf of Matthew Brindley.

AOB

Bethan Edwards from Marie Curie Cymru updated the group on its and MND Association's petition with the Senedd Petitions Committee calling on Welsh Government to provide a timeline, funding and staff to deliver a new End of Life plan considering the current one ended in March. The petition reached over 2,200 signatures and was formally introduced to the Petitions Committee on 25th April and they have sent it to the Health Minister for discussion. The three key recommendations in the petition are to ring-fence spending for the end of life care programme for the next three years, make sure there's enough people and capacity in Government working on the programme considering there's a stark difference in capacity between EOLC and cancer, and lastly to have an implementation/action plan for the QS.

Mark Isherwood MS thanked everybody for joining the CPG meeting, with special thanks to those who provided compelling and often personal testimonies of their experiences during the pandemic. He reminded everybody that the 7th July is the CPG Annual General Meeting and looked forward to seeing people there.

Next meeting dates:

7th July, 12.00-13.30 (AGM)