

GTB Gofal Hosbis a Lliniarol 13 Ionawr 2022, 12.00-13.30yp
 CPG Hospice and Palliative Care 13 January 2022, 12.00-13.30pm
 Cofnodion | Minutes

Experiences of end of life during the pandemic
 Evidence session 2: End of life care in care homes

Yn bresennol | Attendance

Mark Isherwood MS	Ataf Hussain MS
Peredur Owen Griffiths MS	Rhun ap Iorwerth
Jane Dodds MS	

Lewis Clark, Ty Hafan & Ty Gobaith	Laura Hugman, Paul Sartori Foundation
Tracy Jones, Ty Hafan	Andy Goldsmith, Ty Gobaith
Deborah Ho, Ty Hafan	Lowri Griffiths, Marie Curie Cymru
Bethan Edwards, Marie Curie Cymru	Anna Tee, Macmillan
Emma Saysell, St Davids Hospice Care	Gethin Rhys, Cytun
Grant Usmar, Hospice of the Valleys	Nicola Kearney, Hospice of the Valleys
Mary Wimbury, Care Forum Wales	Debbie South, Caron Group
Kim Ombler, Glan Rhos Nursing Home	Heather Ferguson, Age Cymru
Huw Owen, Alzheimer's Society	Janette Bourne, Cruse
Liz Andrews, City Hospice	Trystan Pritchard, St David's Hospice
Melanie Minty, Care Forum Wales	Sian Guest, MNDA
Tom Davies, Macmillan	John Moss, NHS Collaborative
Dominic Carter, Hospice UK	Rachel Williams, Parkinson's UK Cymru
Ryland Doyle, Mike Hedges MS	Rhys Taylor, Jane Dodds MS
Brody Anderson	Heather Price

Ymddiheuriadau | Apologies

Llyr Gruffydd MS	Rhys ab Owen MS
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Welcome from the Chair, Minutes from the previous meeting and matters arising

Welcome to the second deep dive evidence session, this week looking at the experiences of end-of-life in care homes during the pandemic. We're joined by a number of speakers today, to give an insight into their experiences – and contact details are available from Lewis, for those who wish to follow-up on anything brought to light today.

A big thank you to Catrin Edwards who has moved onto pastures new with Carers Trust. Catrin undertook great work to support the CPG and to make it as effective as it is. While Hospice UK seek her replacement, Lewis Clark from Ty Hafan and Ty Gobaith will be supporting with the Secretariat role. For any queries, please contact Lewis.

The National Bereavement Framework, as discussed in previous meetings has now been published, and applications for the Bereavement Grant have now closed. We are awaiting further information on the results of the grant applications.

On the topic of bereavement support, where there is a great deal of overlap with the Hospice sector, several Members made contributions on the record before Christmas regarding third sector bereavement support specifically for children, notably Ty Hafan, Ty Gobaith and 2 Wish Upon A Star. Thank you to those Members for their support – and to our wider membership who has supported that work.

Deep dive, evidence 2: Experiences of palliative and end of life care in a pandemic – End of Life in Care Homes

A Personal Experiences:

Nicola Kearney, Hospice of the Valleys:

Nicola's full presentation has been provided as a separate attachment for ease.

Nicola, a Palliative Care Clinical Nurse Specialist for Hospice of the Valleys, in Blaenau Gwent, South Wales – whose role covers 14 care homes in the area, provided us with her own experience of delivering end of life care during the pandemic.

Nicola spoke of some of issues and challenges faced:

- Blanket DNRs in place, GP's deeming residents not fit for resuscitation or hospital admission.
- We had difficulties sourcing end of life medications (diamorphine/ midazolam/ hyoscine). Sometimes death happened before medications were available. In particular, the short supply of hyoscine for secretions was difficult to obtain with pharmacies running out of stock.
- Some homes had difficulty sourcing PPE initially, and staff were advised to reuse face masks by placing a paper towel underneath their mask due to limited supply. We were fortunate at Hospice of the Valleys as the health board provided us with plenty of stock and have done throughout.
- Staff in care homes purchased their own uniforms/scrub.
- Difficult having unwelcome and uncomfortable conversations with family and patients whilst wearing PPE, which felt extremely impersonal.
- Staff were fearful and felt helpless to support Patients. Patients with pyrexia would receive paracetamol suppositories for elevated temperature, but staff were advised not to administer them due to the nature of the unknown virus. We were advised not to use fans due to the risks of spreading the virus. The unknown was extremely challenging.
- The residents' homes began to feel much more institutionalised like a hospital than their homes – signs, hand washing, PPE, etc.

Rachel's Experience:

Nicola's colleague, Rachel, worked in a care home for the majority of the pandemic, and also shared with the group her own experiences:

"In this particular home, it was 18-months into the pandemic before they received their first positive covid-19 test.

“This particular lady had come into the home just before the first lockdown, having previously been in hospital. The difficulties associated with her death had really struck me – particularly ensuring that family support was available to her during end of life. The husband had declined a visit because the best that could be offered was a very short visit. He said that if he came he wouldn’t want to leave her side.

“During end of life, we sat with the lady and comforted her as best possible – albeit no replacement for families. One day we received a call from her daughter who mentioned that the lady loved singing and requested if she could sing to her mum over the phone. We obviously allowed that and it was clear how much she enjoyed the experience – the daughters own personal way of connecting with her mum.

“The phone rang again shortly after, this time the husband had asked if he could also sing to his wife.

“It was an extremely moving experience for all of the staff – and highlighted just how challenging end of life in care homes during the pandemic had been – separating families during extremely difficult times, and serves as a reminder that challenges existed in other settings than hospitals.”

Rachel reiterated how proud she was to have worked in care homes during the pandemic – but also just how difficult many of these experiences were.

The Chair, and group, thanked Rachel for sharing such a moving experience – which really did highlight how difficult providing end of life care had been.

A Care Home Perspective:

Mary Wimbury (Chief Executive Care Forum Wales):

Mary, the Chief Executive of Care Forum Wales, who support around 450 care providers right across Wales, noted that the above experiences really resonated with what the sector had experienced and felt as a whole.

Mary highlighted that the normal support was not available, and residents were not able to go to hospital as they may have done in other times. It was noted that one of the biggest challenges was the constant unknown of what was going to happen next.

Mary shared a story from early into the pandemic:

On 25 March a resident became poorly, the out of hours nurse was called and the resident was taken to hospital, a 45 min trip each way. As soon as he arrived the home was told he wouldn’t be admitted as he had covid symptoms, and was at end of life. Two hours after leaving the home, he returned.

Due to the concerns around his potential covid symptoms they sought to quickly access PPE – but none was immediately available. After 5 hours of chasing, they accessed some flimsy masks and there was a real concern about staff, other residents and families.

Eventually someone from LHB came out to do the covid test, and test up to maximum of 3 residents who had symptoms - but after that presumed all others had covid.

The resident eventually passed away on the Friday (having fallen ill on the Wednesday). Nobody could confirm how long the body had to be left before the undertaker could collect; how long to leave room clear and ventilated. The undertaker said they had to seal the deceased mouth and noses; or wrap them tightly in bed sheets and leave at nearest exit. **The home couldn’t believe what they had been told.** Another undertaker eventually removed the body wearing full PPE and using a body bag.

Mary highlighted that the above story is one of many – and goes to show the lack of clarity and lack of communication that was available. It is appreciated that this was early into the pandemic when there were more unknowns – but serves to highlight the difficulties that homes faced when tackling the death of a resident due to covid.

The Chair thanked Mary for sharing that experience with the group.

Kim Ombler (Glan Rhos Nursing Home):

Kim also shared her experiences of providing end of life care in homes during the pandemic and shared the story of a retired nurse - known to Glan Rhos - who was at end of life but living with her family at home.

The lady decided that being at home was not fair on her family so contacted the district nurse and asked if she could move into Glan Rhos – as she said she would feel comfortable there. The lady died a week and a half later and Kim was with her on her last day, with her family unable to visit.

During end of life the lady who was on a syringe driver became agitated and was fighting. The staff at the home did their best to make her more comfortable but were told they had to wait for the medication to work. She died after 6 hours of fighting. Kim stated that this individual was let down by the system, with a lack of contact, communication and clarity. She experienced end of life uncomfortably, without her family and with the care home provided little to no support. They were left to their own devices.

Debbie South (Caron Group):

Debbie South, from Caron Group who have 11 homes across South and Mid-Wales, also stated that the experiences of the other speakers resonated and that herself and colleagues had similar experiences.

Debbie stated it was clear from the outset that there was a theme of Protect the NHS – while the social care, community and care home sectors were completely forgotten about.

Care homes were often leaned on to take in patients who had or were suspected to have covid – which placed care home staff under enormous pressure – and created real concerns for end of life patients and the families of those at end of life.

During the pandemic, homes were able to only offer 15-minute visits for the families of someone at end of life. This caused great difficulties both for those families and for staff. PPE was another problem – it dehumanised end of life and family visits.

One of the most profound experiences for Debbie was during the second wave of the pandemic. One of their care homes was free of cases – then overnight 33 staff tested positive and in two-to-three days 35 of the 45 residents also tested positive. The home was in chaos, with little to no staff to provide care.

During this period, there was one elderly resident who was at end of life and was isolating in her room due to the outbreak. Debbie heard noises of distress coming from her room on this particular day and found the lady had vomited considerable amounts of blood. It became apparent that Debbie was unable to provide the support and comfort that this lady needed due to PPE and the risk of further infection. The best she could offer was to lay next to her on her bed, while still dressed in full PPE. In 38 years as a nurse, Debbie said this was one the most awful things she has experienced.

Debbie, like others, stressed that there was not enough priority given to the care home and community settings – with all of the support going to the NHS. It felt like they had no support.

While the pandemic has moved on to a certain degree – and they're in a better place now but that support is still needed.

Open Discussion & Questions

The Chair thanked Debbie – and all of the speakers – for the deeply moving and personal experiences which were a great insight into the realities and challenges for care homes. Mark then opened up the debate to Members for any questions.

Altaf Hussain MS: Questioned who was encouraging homes to take covid positive patients and who was instructing that patients were DNRs? Altaf also asked if there is now resuscitation equipment available to all care homes? And queried why we're only now hearing of these experiences – and if meetings were held with key stakeholders at the time?

Mary Wimbury (CFW) responded: Care homes were taking patients untested – which is where the incidents occurred. Some homes were reportedly threatened with being reported to Care Inspectorate Wales if they did not take them. With regards to sharing experiences – care homes have been trying to act on what is in front of them within a very fast moving environment. Mary added that while things have improved, the sector is now running on empty and greater support is needed.

Altaf Hussain MS: Suggested that we, as a group, should write to the Health Boards and seek a meeting to address some of these concerns.

Chair: Noted that these evidence sessions will shape a report that can be issued to the Minister and to the seven LHBs.

Picking up on what was said by the speakers, Iain Mitchell – St Kentigern Hospice CEO - added that care homes are part of the community and wider system of health and social care. They should have and should be supported accordingly. Not just the NHS should be a priority.

Dom Carter (Hospice UK) asked: What could help to alleviate the strains on care home staff; and what still needs to be improved on?

Kim Ombler: There needs to be a more formal approach to training care homes in end of life care – or an end of life pathway. There is no clear indication as to when training will be provided with her care staff taking it upon themselves to stay up to date. There needs to be more formal guidance.

Nicola Kearney added: Carers within the care home sector also need to be afforded the opportunity to reflect on their experiences from the last two or so years. While we are lucky that there is some clinical supervision and support in place – there needs to be greater opportunities to access support for care homes staff.

The Chair also flagged the issues around a postcode lottery of services across Wales, financial support and access to PPE. He asked if there were any other issues that should be commented on within the report?

Mary Wimbury: Added that while there are programmes of support through Social Care Wales and the RCN – staff need the time and capacity to step back and actually access these services. Too many people are leaving the sector as they need a break. Care home staff wages is another issues in this – and while the commitment that all will access a minimum living wage is welcomed, it is still a big strain on the sector. Further to this, Mary flagged the issues of respect for the social care sector – with health and the NHS often prioritised. There needs to be greater respect and coproduction between the two.

Ongoing issues and updates

National Programme for End-of-Life Care/Quality Statement

Work to establish a national programme board for end of life care has commenced and a task and finish group has been established. The task and finish group has met three times and work to develop a quality statement for end of life care, in line with the National Clinical Framework is said to be progressing well.

Service user feedback is being sought prior to the quality statement being submitted to the end of life care board and then the Health Minister for sign off. The final quality statement for end of life care will need to reflect the recommendations from a central pause and review of all quality statements which is currently ongoing.

Voluntary Hospice Funding Review

Phase One of the Voluntary Hospices Funding report is complete. Welsh Government has agreed to: Fund children's hospices at a 21% contribution level of agreed care costs (£0.9m); and to Increase adult hospices' funding for the estimated inflationary impact, on the funding formula approach from 2010, for hospice beds and community service costs, and to fund the financial impact of the implementation of additional beds established since then (£1.3m).

This additional £2.2m for hospices has been included in the draft budget and will be implemented on a recurring basis from April 2022.

Bereavement Framework/Bereavement Support Grant

The bereavement framework sits within Welsh Government's vision is for a Compassionate Wales. This vision is set out within the National Framework for the Delivery of Bereavement Care in Wales which was published on Thursday 28th October 2021.

The framework is designed primarily for commissioners and providers of bereavement services and has been overseen by a National Bereavement Steering Group consisting of a wide range of statutory and voluntary stakeholders. It sets out core principles; minimum standards; and a range of actions to support regional and local planning.

Implementation of the framework is being supported by a £1m Bereavement Support Grant for third sector bereavement providers. Successful organisations are scheduled to be notified week commencing 17th January.

Welsh Government response to CPG report

The Minister has responded to last year's CPG report on the role of the Compassionate Cymru programme in building capacity and resilience within the community. Welsh Government have accepted all four recommendations (see below) and outlined a range of measures that are aimed at helping to deliver them.

The CPG will continue to work with Compassionate Cymru partners and Welsh Government to keep the spotlight on these issues.

1. Engaging and supporting racialised communities
2. Making it everybody's business to care before an expected death and into bereavement
3. Caring for families and carers
4. Leading a national conversation with the people of Wales about 'what matters' at the end of life

AOB

Chair: A week today is the funeral and bereavement Cross-Party Group. If anybody wishes to attend then get in touch with Lewis or myself.

Next meeting dates:

17 March 2022, 8:30-9:30

7 July 2022, 12-13:30 (AGM)