

GTB Hosbis a Gofal Lliniarol 27 Ebrill 2023, 2.00-3.30pm

CPG Hospice and Palliative Care 27 April 2023, 2.00-3.30pm

Spotlight on trans and gender diverse communities experiences of end of life care, what the UK COVID-19 Inquiry means for Wales, and update on Welsh Government's end of life funding review

Cofnodion | Minutes

Yn bresennol | Attendance

Mark Isherwood MS	Mark Major (Altaf Hussain MS)
Owen Thomas (John Girffiths MS)	Steven Skivens (Peredur Owain Griffiths MS)
Eleri Cabbage (Lynne Neagle MS)	Ryland Doyle (Mike Hedges MS)

Ceridwen Hughes, Same But Different	Emma Saysell, St David's Hospice Care
Dominic Carter, Hospice UK	Catrin Glyn, Carers Trust Wales
Matthew Brindley, Hospice UK	George Parish Wallace, Alzheimer's Society
Tracy Jones, Tŷ Hafan	Laura Hugman, Paul Sartori Hospice at Home
Janette Bourne, Cruse Bereavement Support Cymru	Dr Idris Baker, National Clinical Lead PEOLC
Ellen Greer, St Kentigern Hospice	Anna-Louise Marsh-Rees, Covid-19 Bereaved Families for Justice Cymru
John Moss, Compassionate Cymru	Gethin Rhys, Cytûn Churches Together in Wales
Grant Usmar, Hospice of the Valleys	Glenn Page, Macmillan Cancer Support
Alyson Francis, Welsh Government Director for the COVID-19 Public Inquiry	Liv Warnes, Hospice UK
Jenny-Anne Bishop OBE, Unique Transgender Network	Hannah Buckingham, Macmillan Cancer Support
Sian Emlyn Edwards, MS staff	Kirsty Rees

Ymddiheuriadau | Apologies

Steve Parry, Nightingale House Hospice	Liz Booyse, City Hospice
Rhun ap Iorwerth MS	Trystan Pritchard, St David's Hospice
Jon Antoniazzi, Marie Curie	Tash Wynne, Marie Curie
Andy Goldsmith, Ty Gobaith	

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

Mark welcomed everybody to the meeting, in particular the guest speakers.

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

Mark updated members on progress against actions:

- Following consultation with Hospices Cymru the CPG responded to the Minister for Health and Social Services on the cost-of-living challenges facing hospices. In the letter it welcomed her support calling on Health Boards to apply equitable uplifts to contracted hospice services, her commitment to continue the £2.2 Million in funding for hospices, and to consider agenda for change, staff retention and service level agreements as part of the phase three funding review. However, the CPG did call again for urgent action to address the immediate pressures facing hospices, including:
 - Prioritise greater funding support to mitigate the impact of the NHS pay awards on the hospice sector.
 - Reconsider the decision not to accept the phase two recommendation for a one-off payment to support energy and fuel costs for voluntary sector hospices.
 - Apply inflationary or equitable uplifts to the £2.2 million already committed by Welsh Government to the hospice sector.
 - Develop a long-term sustainable funding framework and partnership with Welsh hospices.
- The UK Secretary of State for Business, Energy and Industrial Strategy did finally respond to the group, but unfortunately they didn't prioritise the need for enhanced energy support for hospices under the Energy Bills Discount Scheme. The CPG also wrote to the Chancellor highlighting these issues and are still waiting for a response.
- Continue to communicate with ADSS Cymru who apologised for not finding a representative to talk to the CPG but still say they are committed to doing so. Disappointing it is taking so long for ADSS Cymru to constructively engage on improving access to short breaks for children with life-limiting conditions and their families, but will continue to push for this to happen.
- CPG inquiry report into experiences of palliative and end of life care in the community during the COVID-19 pandemic has been shared widely but still has to be shared with health boards and HEIW.:
 - Informed a well-attended hour long debate in the Senedd which received cross party support.
 - Welsh Government provided a formal written response to the CPG inquiry accepting all of its recommendations either in full or part.

- The National Programme Board for Palliative and End of Life Care have discussed its findings and recommendations at a recent meeting.
 - Received a formal response from the UK COVID-19 Inquiry to our recommendation that it needs to recognise and prioritise the experiences of people in Wales. Unfortunately, its position remains unchanged in terms of extra focus and capacity to more meaningfully include Wales.
- Wrote to the Interim Chief Executive of Betsi Cadwaladr UHB asking for more information and better engagement regarding access to specialist palliative care in the Health Board.
 - In contact with hospices and CPG members regarding the terms of reference for our next inquiry into sustainable Welsh hospices.

Ongoing and arising actions

Date	Action	Status
27 th April	Write to Jane Hutt and Eluned Morgan (copying in the National Programme Board) and ask what Welsh Government is doing to improve palliative and end of life care for trans and gender diverse communities, including how they intend to respond to the Hospice UK report 'I Just Want to be Me'.	Ongoing
27 th April	CPG should explore how they can help provide evidence on Welsh palliative and end of life care experiences for module 3 of the UK Covid-19 Inquiry and the new Senedd Covid-19 inquiry Committee	Ongoing
26 th Jan	Share CPG inquiry report with Health Boards and HEIW and run follow up CPG sessions on progress towards meeting key recommendations.	Ongoing
27 th Oct	Continue to engage the Association of Directors of Social Services Cymru on improving family access to respite.	Ongoing

How can the UK Covid-19 Inquiry learn from Welsh experiences of end of life care during the pandemic

Anna-Louise Marsh-Rees, Group Lead for Covid-19 Bereaved Families for Justice Cymru talked about her father who died of Covid in 2020. She described it as a brutal experience that you couldn't call end of life care.

Since then the group have called for a Wales specific inquiry and pushed for palliative and end of life to be included in the themes to be covered by Welsh Government. The UK Covid-19 Inquiry is giving very little consideration to what happens before, during and after death. Anna-Louise said that while they want a Wales specific inquiry, they also want to make a difference and are working more broadly with the likes of the National Bereavement Steering Group who have agreed that there should be mandatory palliative and end of life care training for all health and social care staff.

Palliative and end of life care is in module 3 of the UK Covid-19 Inquiry and the group would welcome the support of CPG members in preparing evidence for this stage. To date there are very few Welsh organisations who have core participant status and the group would welcome

others getting more involved. They have also asked for Hospice UK to have rule 9 status in the Inquiry.

Anna-Louise said they have had no statements from Welsh Government on module 1 despite the module being only 7 weeks from starting and that they have requested Welsh Government urgently release evidence to enable scrutiny.

Alyson Francis, Welsh Government Director for the COVID-19 Public Inquiry provided a general overview of how the UK Covid-19 Inquiry is structured into a series of modules covering a wide range of topics. Module 1 will cover pre-pandemic planning, module 2 administrative and political decision making, module 3 looking at health care systems.

When the Inquiry starts a module it opens up applications for 'core participant status' and can also send rule 9 requests to organisations requiring them to give evidence. So far Welsh Government have provided over a thousand statements to the Inquiry which they then process and release to other participants.

Alyson said that the Chair of the UK Covid-19 Inquiry has met with Anna-Louise and the Covid-19 Bereaved Families for Justice Group and that there is a sharing experiences section on the Inquiry website where people can submit evidence.

Gethin Rhys described Cytûn/Churches Together in Wales experience of submitting evidence to the inquiry, describing the challenges with the quantity of work associated with being a core participant. He said they had found a half way house and submitted evidence without becoming a core participant. He recommended asking the solicitor for the UK Covid-19 Inquiry for permission to submit info.

Mark Isherwood thanked Anna-Louise and Alyson for taking the time to speak to the CPG and asked Alyson why there had been no Welsh Government disclosure of evidence to date?

Alyson said Welsh Government had provided a number of statements and that it was up to the UK Covid-19 Inquiry to release info to core participants.

Spotlight on trans and gender diverse communities experiences of end of life care

Liv Warnes, Policy and Advocacy Officer from Hospice UK presented the key findings and recommendations from Hospice UK's 'I Just Want to be Me' report exploring end of life care for trans and gender diverse communities:

hospiceuk

I just want to be me:
Trans and Gender Diverse Communities' Access to and Experiences of Palliative & End of Life Care

www.hospiceuk.org

1

Leading up to the report

- Previous work had highlighted inequity for LGBTQ+ communities
- Conducted two surveys in partnership with GIREs
- Conversations and interviews with people with lived experience

Being Ready

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2

I just want to be me
Trans and Gender Diverse Communities' Access to and Experiences of Palliative & End of Life Care

"I would want to die in a place where I felt comfortable, with the people who I felt comfortable being around. I would need them to know I was trans, and know that they would respect my body and wishes."
Community survey respondent

Tips:
Discuss with a friend what personal care and presentation feels like. They would be comfortable if they are not able to confirm their preferences.

"It's really important that if people hear people accidentally misgendering that they call it out to that it's not always the person having to say 'actually you misgendered me', other people call them out on it, because that's wrong."
Dr Lisa Kemp

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3

Report findings

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4

Planning for the end of life

- 68% answered that being trans/gender diverse had impacted why they thought about their plans and wishes for the end of life and after their death.
- Preparing in order to protect grieving loved ones
- *"I must consider what I need to put in place to prevent family members who do not accept me for who I am having the power to override his decisions in the event of my death. I live in fear that I will die and be buried under a headstone that is not for me, or that my family of origin will organise a religious service against my wishes, where they will speak about me as though I was someone else. The people I love would be deeply hurt by this and I wouldn't be here to protect them."*

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5

Approaching Care Providers

- Many of those filling out the survey expressed anxiety or concern over approaching end of life care providers
- Reasons people cited for their anxiety included previous healthcare experiences, fears their identity will be ignored or they will be discriminated against, and concern over their transition.

Tips:
Palliative and end of life care providers should develop clear guidance on providing gender, identity, and gender diverse care. This must include how discrimination will be handled and how a staff member or volunteer who begins their transition while employed by the provider will be supported.

Display a visible commitment to inclusion in all services to ensure people in need services to access.
Support trans and gender diverse people accessing end of life services in the end of their lives. If it is a bereaving or volunteer who begins their transition while employed by the provider will be supported.
Connect with local trans and LGBTQ+ organisations and community groups.

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6

Retaining Identity and Dignity

- Those who had experiences of end of life care had mixed responses on whether their name and pronouns had been respected, and whether they had access to gender affirming clothing, items and personal care.

Recommendations:

Providers should be encouraged to implement a 'this is me' document, which can be held by the individual or downloaded into digital shared care records, that includes information important to the individual, such as information about their gender, presentation and transition related medical needs.

All NHS and hospice IT and patient information systems should be updated, following consultation with trans and gender diverse communities, to ensure people's name, title, gender and their status are captured and recorded accurately. This must be inclusive of non-binary and gender diverse identities.

Palliative and end of life care services should ensure that intake and referral forms capture an individual's preferred name and pronouns.

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7

Physical care

- Professionals and members of trans and gender diverse communities expressed concern over a lack of medical knowledge specific to trans people in end of life care

Recommendations:

Professional bodies and Royal Colleges should produce up to date guidance on providing medical and clinical care to trans and gender diverse people in palliative and end of life care

"My Dad's gender identity has impacted their care in many ways. When in hospital, she was not offered a shower for ten days and I am convinced this is because of her being trans."
- Rebecca Maylock

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8

Workforce and training

- "A lot of people were willing to learn. The hospice said that my Dad's stay there was absolutely transformative to their service and staff, and that meant the world to us."
- Large majority of those working sectors linked to death, dying and bereavement indicated they were keen for opportunities to learn

Recommendations:

Education providers and those who have responsibility for developing staff training curricula should ensure health and social care staff receive pre-registration training on gender, including understanding what it means to be trans or gender diverse, and trans and gender diverse healthcare needs.

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9


Thank you!

- Read the full report and all recommendations – <https://www.hospiceuk.org/publications-and-resources/i-just-want-be-me>
- If you're interested in working in this area or have good practice to share please get in contact - o.warnes@hospiceuk.org

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10

Jenny-Anne Bishop OBE from the Unique Transgender Network (North Wales & West Cheshire) presented on some of the key issues facing Trans and Gender Diverse People at end of life:



Jenny-Anne Bishop OBE B.Sc. (Hons)
Older Trans* Woman (Transsexual Woman)

Chairperson, Outreach, and Training coordinator
The Unique Transgender Network North Wales

**In this presentation we use the umbrella term 'Trans*' to include all those who identify as Trans, Gender Variant, Gender non-conforming, Gender Fluid, Gender Diverse, Non-Binary or Non-Gender & in some cases Intersex people.*

Setting the Scene

- 75% of Older Trans people live alone
- 1 in 5 have no-one to contact in a crisis
- Many are living with isolation & loneliness.

Setting the Scene

Social & Health Issues for Older Trans* / Gender Variant Peoples

- The Number of UK Gender Diverse people who are 50+ is estimated at over 200,000 (Approx. 12,000 in Wales)
- They are a largely unrecognised, and reluctant to identify group whose needs are often neglected being largely undocumented
- Their potential health, social & care providers are mostly untrained in awareness of their appropriate health, social and care needs

Multiple fears for Older Trans People who may need care

- Of coming out to residents and staff
- Funeral wishes not respected
- Being forced into the wrong gender
- Losing touch with gender identity – 'recloseting'
- If dementia comes, privacy is more exposed
- Placing expression of gender identity in the control of others
- People won't know or understand our history
- What happens if I lose the ability to know who to trust?
- What happens if I forget I'm Trans?
- Personal care /health screening – triggering Gender Dysphoria
- Not being treated with dignity
- Will staff recognise my 'family of choice'?
- Staff not supported in addressing other residents' prejudice
- Discrimination or abuse by staff
- Will people see staff in my notes that I don't want shared?
- Being "Outed"
- Bullied or ostracised by other residents

End of life Issues

- Some Health professionals are very uncomfortable in providing palliative care services to Trans people
- Resolving difficult Family issues including Exclusion & respecting the Persons Wishes
- Power of Attorney and Death Certification
- Need to have Sympathetic Executors
- Lack of Knowledge on Legal Matters, Benefits and inheritance
- Needs to be Access to Advocates for ALL.

Lack of Family Support

- Many older Trans people often live alone, are less likely to have a partner or children and are often estranged from their family, preventing them using these informal care support systems.
- They have to use formal systems to support them within their homes or within some type of Sheltered Accommodation, Hospice or other Residential Care institution’.
- Only those totally Out & Privileged may have the confidence to obtain good service & support

End of life Issues- Families may:

- Prevent access to long term Partner / “Family of Choice”
- Ignore “Last Wishes”
- Refuse to acknowledge a person’s Trans life & Identity in the death certificate and at the funeral
- Arrange the funeral far away at inconvenient time/ place to exclude community friends / Family of Choice”
- Erase the partner’s history and Not recognise their grief & support needs

Service User Comments

“Feelings are an important aspect of health and Wellbeing so they should be considered. For too long Trans people have been shown little consideration, so now is the time to focus attention on such an important issue.”

“My concern is not feeling safe and unable to just be myself.”

“It is really important that training on Trans awareness is made available to staff in all Residential homes, Hospices, etc.”

Service User Comments

“ The day I need a care provider is the day I activate “my end of life plan”

“I am concerned about what help and support I will get when I am unable to make decisions for myself. I think I would rather die than live without dignity or respect.”

“I am very scared about my future and quality of my life if I get dementia.”

“I wish I’d had the courage to live a life true to myself and to express my true feelings, not the life others expected me to live”

Good Practice

“Respecting a person’s individuality & preserving their dignity are the cornerstones of person-centred care.”

Attending to a person’s physical, social, spiritual, psychological and emotional needs is what keeps a person comfortable

The need for family/chosen family & supportive carers are very important to everyone at the end of their life.

Encourage everyone to make a Care Plan and make the benefits clear to everyone

Finally provide appropriate care and respect after death.

Impact on the Health Care of Trans People

49% Won’t consult their GP [NHS Wales Survey]

Trans people are less likely to undergo routine screening or testing & preventative measures; thus avoiding consulting Health Professionals even when their symptoms could indicate cancer or other serious health needs!

Good Practice

The great experiences of the patient being able to be who they are, with the people they love, in the place they want to be, in their last moments, can provide no better reason for improving our understanding and taking action on the differing needs and requirements of each individual.”

(Scott Durairaj - Head of Patient Experience Mental Health and Learning Disability; NHS England)

Our recommendations for change

Top three wishes & expectations from trans interviewees:

- 1. Increased knowledge and trans awareness** - among GPs and all healthcare workers, by providing training at both foundation and in work(CPD) levels.
- 2. Local Gender Clinic** – smoother process, decentralised/closer to home, less hurdles to jump, less bureaucracy and personal expense
- 3. Better standards of care** – inc. medical records and correspondence that matches names & gender ID, reminders about needed sex-specific screening (e.g. breast/ AAA/ prostate cancer screening)

Overall, seeking dignity, respect & fair treatment in later life across all health & social care services

The way forward for Practitioners

- **Systematic working**
- **Person-centred approach**
- **Being pragmatic when needed**
(Sloan & Safer, 2018)
- **Heightened Reflection**

Slide courtesy Helen Bichard

The way forward for Practitioners

- **Systematic working**
 - Training care staff, nurses, doctors
 - E.g. body-based mindfulness may not be appropriate; reminiscence may return client to challenging period
 - Inviting in Third Sector experts
- **Person-centred approach**
 - Life story to follow like a passport
 - How do THEY think issues like personal care should be handled?
 - Advance wishes for end of life
 - Being prepared to work with clients therapeutically on themes such as shame, loss, regret, loneliness
 - Compassion/Acceptance-based Models
- **Being pragmatic when needed** *(Sloan & Safer, 2018)*
 - Signposting to support groups
 - Role plays and coaching
 - Problem-solving and decision-making
 - Supporting families *(Boedecker, 2018)*
- **Heightened Reflection**
 - e.g. noticing ones own discomfort with non-binary *(Hopwood, 2018; Leonard & Grouss, 2018)*
 - Use of peer networks if possible *(BPS, 2012)*

Slide courtesy Helen Bichard



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Mark Isherwood thanked Liv and Jenny for their presentations and said he would be interested to hear how Hospices Cymru and others delivering palliative and end of life care have responded to this work. He suggested writing to the Minister for Social Justice, Jane Hutt MS and possibly the Minister for Health and Social Services, Eluned Morgan MS.

Jenny-Anne said she had spoken to Jane Hutt and Hannah Blythyn but unfortunately there had been little action in response.

Mark Isherwood agreed with members to write to Jane Hutt and Eluned Morgan and ask what Welsh Government is doing to improve palliative and end of life care for trans and gender diverse communities, including how they intend to respond to the Hospice UK report.

Update on Welsh Government response to phase 2 funding review recommendations and plans for phase 3 funding review

Dr Idris Baker, National Clinical Lead for Palliative and End of Life Care thanked Liv and Jenny-Anne for their presentations and suggested that the National Programme Board pick up this issue at some point.

Idris said that they were working with Welsh Government and that ongoing detail was being added to recommendations 1 and 2 from the phase 2 funding review. He also welcomed the CPGs focus on the cost of living recommendation for hospices.

The deadline for the phase 3 review is January 2024 and the Minister has asked them to look at the longer term projections for palliative and end of life care as part of the review. Idris said

they were determined that funding would back the phase 3 recommendations and that the review needed to be decisive as there would be limited opportunities to do such a piece of work afterwards.

Idris said the scope of the review is wider than just the hospice sector. He recognised the frustrations some experienced with phase 2 and said they have more time and capacity to engage better on phase 3.

Mark Isherwood asked if the phase 3 review will address variations in statutory funding of Welsh hospices across Wales and compared to other parts of the UK?

Idris hoped that the phase 3 review would address this, but through the lens of value in terms of population need etc. The review would like to see a reduction in inequity and variation in access to palliative and end of life care but recognise that this is still largely in the hands of Health Boards. There will still be warranted variation in access to care across Wales but hopefully the review will help address unwarranted variation which they are acutely aware of and determined to tackle.

Grant Usmar, CEO Hospice of the Valleys and member of Hospices Cymru recognised the positive recommendations made in the phase 2 review and the Minister's recent response to Hospices Cymru, but said hospices were disappointed that Welsh Government had decided not to action the funding review recommendation to provide a one off payment to hospices to help with cost of living pressures. The general feeling was that phase 2 could have been done more collaboratively and done more to address the staffing cost pressures hospices are facing as a result of ongoing NHS pay awards.

Grant said that Hospices Cymru was willing and eager to engage with the phase 3 review to help support a more sustainable hospice sector in Wales, but emphasised that they need support right now to even stay still. He said the next funding review needs to revisit the current funding formula and definitions of 'core' and 'key' services. It also needs to clarify how hospices are part of Welsh Government's wider focus on coordinated community care.

Terms of reference for CPG inquiry into sustainable Welsh hospices

Matthew Brindley summarised the proposed questions for a future inquiry into sustainable Welsh hospices which would be circulated after the meeting.

Mark Isherwood suggested the inquiry include a focus on how hospices are being involved in the design and delivery of services in accordance with the 5 ways of working identified in the Well-being of Future Generations (Wales) Act 2015 and the requirements of the Social Services and Well-being (Wales) Act 2014.

AOB

Next meeting is on 13th July, 3.00-4.30pm and will be hybrid with a meeting room booked in the Senedd for those who want to attend in person.