

GTB Hosbis a Gofal Lliniarol 26 Ionawr 2023, 3.00-4.30pm CPG Hospice and Palliative Care 26 January 2023, 3.00-4.30pm

Launch of CPG inquiry report into experiences of palliative and end of life care in the community during the pandemic, spotlight on access to short breaks for children with life-limiting conditions, and access to care at home out-of-hours in Wales

Cofnodion | Minutes

Yn bresennol | Attendance

Mark Isherwood MS	Mark Major (Altaf Hussain MS)
Huw Iranca Davies MS	Steven Skivens (Peredur Owain Griffiths MS)
Eleri Cabbage (Lynne Neagle MS)	Ryland Doyle (Mike Hedges MS)

Ceridwen Hughes, Same But Different	Liz Booyse, City Hospice
Dominic Carter, Hospice UK	B Jones
Matthew Brindley, Hospice UK	George Parish Wallace, Alzheimer's Society
Tash Wynne, Marie Curie	Jon Antoniazzi, Marie Curie
Tracy Jones, Tŷ Hafan	Laura Hugman, Paul Sartori Hospice at Home
Ellen Greer, St Kentigern Hospice	Melanie Minty, Care Forum Wales
Janette Bourne, Cruse	Gethin Rhys, Cytûn
Grant Usmar, Hospice of the Valleys	Dr Idris Baker, National Clinical Lead PEOLC
Mary Mitchell	Catherine Hodge, Hospice UK
Andy Goldsmith, Ty Gobaith	Steve Ham, Chair of National Programme Board PEOLC
Glenn Page, Macmillan Cancer Support	

Ymddiheuriadau | Apologies

Emma Saysell, St David's Hospice Care	Russell George MS
Prof Chris Jones (Deputy Chief Medical Officer)	Jayne Bryant MS
Heledd Fychan MS	Heather Ferguson, Age Cymru
Anna Tee, Macmillan Cancer Support	

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

Mark welcomed everybody to the meeting, in particular the guest speakers addressing access to short breaks for children with life-limiting conditions, the launch of the CPG inquiry report into experiences of palliative and end of life care in the community during the pandemic, and access to care at home in Wales during the out-of-hours period

Minutes from the previous meeting were confirmed by Tracy Jones and seconded by Liz Booyse.

Mark updated members on progress against actions:

- Wrote to the Minister for Health and Social Services sharing an advance copy of the inquiry report into experiences of palliative and end of life care in the community during the pandemic. In her response she welcomed the publication of the report, said she would consider its recommendations in conjunction with the phase 2 funding review and committed to sharing the report with colleagues leading on the Welsh Government response to the wider public inquiry into the COVID-19 pandemic to enable it to inform their considerations.
- The Minister also responded to the CPG letter about the cost of living pressures facing hospices and the people they support. In her response she said she is considering the interim recommendations in the phase 2 funding review which include a focus on community and out of hours provision and the impact of the cost-of-living crisis. Her response also said that the final phase 3 funding review (due for completion in January 2024) will consider the issue of service level agreements and annual inflationary uplifts for hospices as part of 'a Wales offer for palliative and end of life care'. The Minister said she would expect health boards to apply equitable uplifts to all contracted services delivering core NHS services, including hospices.
- Before Christmas, the CPG sent a joint letter with the All Party Parliamentary Group on Hospice and End of Life Care to the Secretary of State for Business, Energy and Industrial Strategy, Grant Shapps MP. The letter called on him to extend the length of the current Energy Price Guarantee to two years for households where a person is at the end of life and extend the current Energy Bill Relief Scheme for hospices. The CPG is yet to receive a response from the Secretary of State, however, it has been somewhat overtaken by the recent Energy Bills Discount Scheme announcement which many hospices feel is insufficient and risks their stability.
- Mark updated members that Hospices Cymru discussed out-of-hours issues with the National Clinical Lead at their last meeting and that the CPG were keeping a focus on this issue again today with a presentation on out-of-hours provision in Wales from Marie Curie.

On the cost of living issues, **Liz Booyse said Hospices Cymru** received a similar response from the Minister and that they would be discussing this at their next meeting and would be

happy to provide the CPG with an update on their response. While she welcomed the Minister's response, Liz said that the immediate costs and related workforce challenges facing many hospices in Wales had not been addressed.

Andy Goldsmith said Ty Gobaith/Hope House was disappointed with the Minister's response, especially considering there are no plans for an inflationary uplift to statutory funding for hospices in the current year. This means that the WG funding increase to 21% for children's hospices last year has effectively been reduced to 13%.

Mark Isherwood and the CPG agreed they will respond to the Minister's cost-of-living letter after consultation with Hospices Cymru. He also asked Hospice UK to provide the CPG with an update on UK Government's recent energy support announcement.

Dom Carter from Hospice UK said they were not happy with the recently announced Energy Bills Discount Scheme which provides no ceiling on costs and risks the stability of hospices at a time when their support for the health and care system is critical. He updated members on Hospice UK's campaign writing to MPs to encourage UK Government to change its position and give more reassurance to the hospice sector, and encouraged members to get behind the campaign.

Mark Isherwood said that in his role as Chair of the CPG on Fuel Poverty and Energy Efficiency he was aware of support available to people with energy bills from the British Gas Energy Trust, as well as contacting their supplier. The CPG agreed that they would chase the UK Secretary of State for Business, Energy and Industrial Strategy for a response and consider writing to Treasury, highlighting the key asks from the Hospice UK campaign.

Ongoing and arising actions

Date	Action	Status
26 th Jan	CPG will respond to the Minister's cost-of-living letter after consultation with Hospices Cymru who will be discussing this issue at their next meeting.	Ongoing
26 th Jan	CPG to chase the UK Secretary of State for Business, Energy and Industrial Strategy for a response to its cost-of-living letter and write to Treasury emphasising the need for enhanced energy support for hospices.	Ongoing
27 th Oct	Contact the Association of Directors of Social Services Cymru again with invite to future CPG and possibility of meeting with children's hospices separately to talk about improving family access to respite.	Ongoing
26 th Jan	Share CPG report more widely with the UK COVID-19 Inquiry, health boards, local authorities, HEIW.	Ongoing
26 th Jan	Write again to BCUHB covering the issues not addressed in their previous response to Ceridwen's evidence.	Ongoing
26 th Jan	Steve Ham to put the CPG inquiry report on the agenda for discussion at the next National Programme Board meeting and to consider its findings and recommendations and involve the CPG in the development of the National Programme workplan.	Ongoing
26 th Jan	Consult with hospices on an inquiry into the relationship between health boards and hospices in Wales and draft terms of reference.	Ongoing

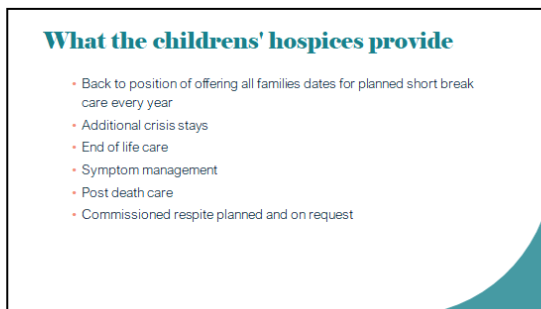
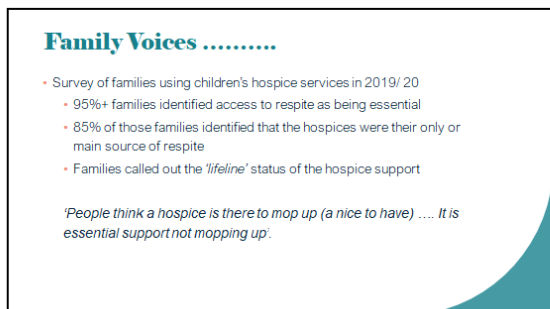
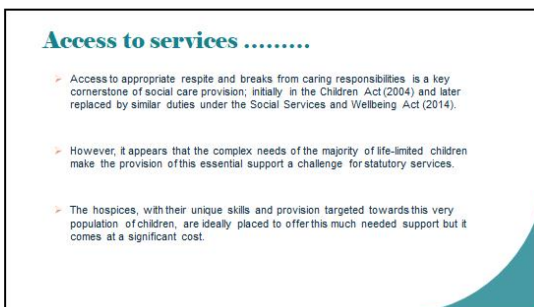
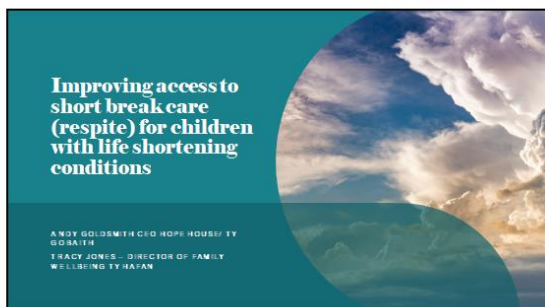
Improving access to short breaks for children with life-limiting conditions and their families

Mark Isherwood welcomed Tracy and Andy. He said unfortunately the Association of Directors of Social Services Cymru couldn't identify a representative to join the meeting despite previously committing to doing so and Matthew making many enquiries. They sent their apologies and said the ongoing pressures in the sector were making it very difficult for anyone to spare the time, but were confident that they would find a rep to join the next CPG.

Tracy Jones from Ty Hafan said the agenda item had been planned with the Association of Directors of Social Services Cymru in attendance and hoped this would still be possible. She highlighted that hospices add huge value across social care as well as health and that many families rely very heavily on hospices for respite. This is in the wider context where local authority provision of respite is often not adequate to meet family needs and many go without a proper support. The hospice offer is designed around providing holistic care and support to families (see slides below).

Andy Goldsmith said children's hospices provide very specialist respite care (see slides below). He highlighted that neither children's hospice in Wales receives regular funding from local authorities for delivering respite, but instead authorities prefer to provide spot support for commissioned care. **Tracy** described there being a big increase in demand for commissioned services in the last year or so. **Andy** said there is misunderstanding between local authorities and health boards about whose role it is to provide respite care and that we need ADSS Cymru here to listen to these issues and respond.

Mark Isherwood said the CPG would continue to chase ADSS Cymru to discuss these issues and **Matthew Brindley** said he would look into a possible meeting between the children's hospices and ADSS Cymru outside of the CPG.



The unique offer

- Access to excellent quality child centred respite is seen as essential by families not just in terms of the expertise needed to care for the child but because of the positive impact on wider family health and well-being. High percentage of families identified that being able to access a respite resource that accommodated the whole family was important to them.
- 79% of respondents from Family Voices survey saw the family focused nature of respite (ability to stay as a family) as something that made a difference to them.
- *"..... it was the family focused respite that was key. We couldn't have just left our 'child' somewhere, being able to stay as a family made it possible to get the break we needed."*

"These places are essential to families like ours, to the children and the families, the whole family not just the child. They are the ones that keep us from breaking."

Launch of CPG inquiry report into experiences of palliative and end of life care in the community during the pandemic

Mark Isherwood welcomed the publication of the CPG inquiry report into experiences of palliative and end of life care in the community during the pandemic and thanked Matthew for pulling the report together and members for their involvement and support.

Matthew Brindley thanked everybody who was involved in the inquiry and gave a short presentation summarising why the CPG carried out this work and it's key findings and recommendations (see slides below):

Cross Party Group on
Hospice and Palliative Care

Inquiry: Experiences of palliative and end of life care in the community during the COVID-19 pandemic

January 2023

'To give people and organisations at the very sharp end of the pandemic a voice and a platform, to learn from their experiences of end of life care at home and in care homes so we are better prepared for the challenges of the future'

www.hospiceuk.org

Pandemic and long-term context

32%↑ Deaths in private homes in Wales were 32% higher than the previous five-year average. This is a trend which has largely continued throughout 2021 and 2022.¹⁴

In Wales, specialist palliative care was recognised as paramount to the Covid-19 pandemic response. Crucial to future sustainability and the ability to deliver, will be a recognition of the positive effect of specialist palliative care as part of a value-based healthcare system.

End of Life Care Implementation Group, Review of Specialist Palliative Care Services¹⁵

2x The long-term projections to sustain current trends in preference for end of life care in the community estimate that community palliative care and care home capacity will need to double by 2040.¹⁶

www.hospiceuk.org

Key findings

- Hospice and palliative care played a critical role in the pandemic response and was supported by a wave of community engagement and action. However, the massive increases in demand for care in the community revealed weaknesses in pre-pandemic planning.
- Many people faced difficulties accessing end of life care at home and in care homes, increasing existing inequalities in palliative care and leading to some devastating experiences, including complex bereavement.
- Health and social care workers went above and beyond to support patients and their families at end of life, facilitating a revolution in collaboration, innovation and creative working across primary, secondary and social care.

www.hospiceuk.org

Learn from the pandemic and build on good practice

Recommendation 1
Welsh Government should ensure PEGLC is at the heart of plans for potential future pandemics and work with families and professionals to review how future visiting regulations could be enacted in a more compassionate and consistent way for those with a palliative care need.

Recommendation 2
The findings and recommendations of the UK Covid-19 Inquiry must be informed by the lived experiences of people in Wales and recognise the impact the pandemic has had on the nation's healthcare systems, specifically for people at end of life.

Recommendation 3
The National Programme Board for PEGLC should develop an innovation programme aimed at better capturing evidence and data that consistently records outcomes, facilitates learning and identifies good practice that can be embedded in national policy and local strategy.¹⁷

Recommendation 4
Welsh Government should, as a matter of urgency, develop an electronic patient record with Advance and Future Care preferences and decisions.¹⁸

www.hospiceuk.org

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www.hospiceuk.org

Mark Isherwood and the CPG agreed that the report should be shared more widely, and recommended writing to the UK COVID-19 Inquiry, health boards, Regional Partnership Boards and HEIW.

Mark welcomed **Ceridwen Hughes** and **Mary Mitchell** to the CPG and thanked them for taking the time to talk about their experiences.

Ceridwen described how it took two years for her sisters to recover from the traumatic experience of caring for their mother at home at end of life. She said the impact on them was comparable to PTSD. She believes this could have been avoided if their mother had received better and more coordinated end of life care at home. Instead there was very little information initially available about caring for a loved one at end of life, followed by a failure to identify and address issues with pain in the early days. She described out-of-hours support as being dire then and now, including issues with unmanned phones and answer phones that weren't checked and the new 111 service not improving things. She said she didn't want to make a formal complaint following her experience with her mother, hoping that she would be able to talk to the health board and address and improve the issues through dialogue and engagement. Unfortunately this hasn't worked and she has had no engagement from the health board. She believes that there has to be something that comes from a death that was so horrific.

Mary told the CPG about her and husband Mike's experience of end of life in a care home with dementia during the pandemic. She described how the lockdown was the worst possible thing because she couldn't see him and didn't know what he knew, she didn't know whether he thought she'd put him in the care home and then abandoned him and that was heart breaking. She said she felt angry, angry with the pandemic, angry with lockdowns and visiting restrictions, angry with the disease, that it stole the last two meaningful years of Mike's life and badly effected both their wellbeing. She described Mike as being emotionally starved for the last two years of his life, in the way so many other people were in care homes because their special people weren't there.

Mary said that despite the huge challenges of the pandemic, the care home did their best and were very kind, particularly towards the end when Mike had stopped eating and drinking and his swallowing was bad and he was very distressed a lot of the time. She described one particular carer who would sit there for hours with him and that when Mike passed away, many of the carers came in to give her a hug and were in tears and obviously very fond of him. She

also read out a poem describing how it felt during this difficult period. She described Covid and lockdown as the thief that stole from her and Mike.

Mark Isherwood thanked Mary and Ceridwen for sharing their experiences and expressed his sympathy for their loss. He recommended the CPG write again to Betsi Cadwaladr University Health Board addressing the issues previously raised by Ceridwen. He welcomed **Steve Ham** and **Dr Idris Baker** to the CPG to respond to the inquiry report and people's experiences.

Steve Ham thanked Ceridwen and Mary for sharing their experiences and welcomed publication of the CPG inquiry report. He said the National Programme Board will put the report on the agenda for discussion at its next meeting and offered to consider its findings and recommendations and involve the CPG in the development of the National Programme workplan.

Idris Baker thanked Ceridwen and Mary and said he was upset to hear some of the bad experiences as well as appreciative to hear some positive ones. He said the CPG report touches upon many of the inequalities that exist in palliative and end of life care and that improving data is key to addressing these. He said he would be happy to help address some of the recommendations for the National Programme Board as well as the wider recommendations.

Spotlight on access to care at home out-of-hours in Wales with Tash Wynne from Marie Curie

Mark Isherwood welcomed **Tash Wynne** to the CPG (see slides below):

Mind the gaps...
Out of hours end of life care in Wales

Hospices and Palliative Care CPG, 26 Jan 2023
Natalasha Wynne, Senior Policy Manager, Marie Curie Cymru
Natalasha.Wynne1@mariecurie.org.uk

In this presentation...

- Background & research findings
- Recommendations for change
- Next steps

2
Care and support through terminal illness

Context

NOVICE
Future Vision Cymru
Spirits and Sustenance
The future of care and support through terminal illness in Wales

"Families are saying 'we can manage the daytime, it's the night time'.... The lack of knowledge and understanding about the situation across the country means that we do not know whether the experience of variation is leading to better or poorer outcomes for people in different areas."

GOV.UK
7 day working
Wales is leading the delivery of 7 day working within their services compared to the other nations... [but] little evidence of investment in the CNS numbers during the last decade to support demand and growth in the OOH service"

Quality standard for palliative and end of life care in Wales
The quality standard for palliative and end of life care in Wales is a national standard for care and support through terminal illness in Wales. It is designed to reduce distress and the likelihood of unwarranted admission to secondary care."

- EOLC NPB Phase 2 Funding Review reporting imminently
- PEOLC need increasing; community care a priority; acute pressures

3
Care and support through terminal illness

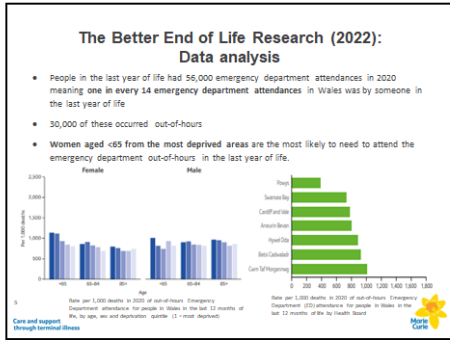
The Better End of Life Research (2022)

A team of academic researchers looked at:

1. UK data on out-of-hours emergency department attendance among people who are in the last year of life
2. Interviews with health professionals about out-of-hours services across the UK
3. A patient and public involvement (PPI) workshop

Better End of Life 2022
Mind the gaps, understanding and improving out-of-hours care for people with advanced illness and their informal carers
Research Report

4
Care and support through terminal illness



The Better End of Life Research (2022): Professional interviews

Common issues:

- Access to medicines and having the right staff to administer them
- Rapid availability and access to equipment
- Availability of care packages, particularly to support discharge home from hospital to die – families have to plug gaps
- Heavy reliance on already stretched district and community nursing, who provide much of the hands-on OOH care
- Often no single point of access to PEOLC services OOH: distressed patients and their families can experience delays and difficulties in being connected to local services and the support they need.

Care and support through terminal illness

- ### Recommendations for change
1. 24/7 PEOLC advice line in every area, as recommended by NICE
 2. Better access to medicines, with a particular focus on rural communities
 3. A workforce that is fit for purpose and a workforce plan based on up-to-date vacancy data and projections of future need
 4. Better access to shared records and care plans through a central electronic repository
 5. Equitable access to PEOLC services with a focus on OOH within the Women's Health Plan
- Better End of Life 2022**
Marie Curie policy commentary on
Healthcare understanding and improving out-of-hours care for people with advanced illness and their informal carers
- Care and support through terminal illness

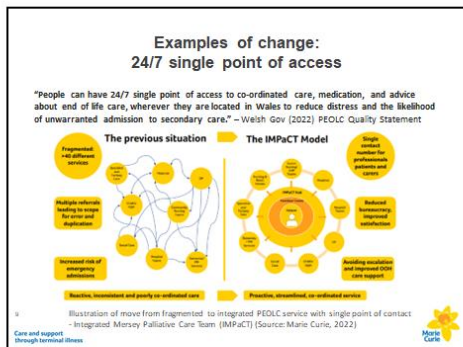
“As far as I can see, the system doesn't work. My dad fell through the cracks. If he hadn't had me advocating for him, I don't know what would have happened.”

If there was a dedicated helpline, it would be so much easier. The way it works now makes it impossible to check on the progress of anything or find out who you need to speak to.

The actual dying part wasn't scary. In the last 48 hours, Dad was comfortable in the hospice. But in the weeks leading up to that point, he was in extreme pain and without dignity. That shouldn't happen to anybody.”

Darren's father Graham, from Port Talbot, had terminal mesothelioma due to asbestos exposure and died in April 2022

Care and support through terminal illness



For more information contact:
Natasha Wynne
Senior Policy Manager, Wales
Email: Natasha.Wynne@mariecurie.org.uk
Follow us on Twitter @mariecurieymnu

Links to the publications cited in these slides can be accessed by clicking on the relevant picture icons.

We're here for people living with any terminal illness and their families. We offer expert care, guidance and support to help them get the most from the time they have left.

mariecurie.org.uk
Charity No. 207694 Registered Office: 200011, Glasgow, G4 0JF

Care and support through terminal illness

Mark Isherwood thanked Tash for her presentation.

Ceridwen Hughes thanked Tash but expressed concern that if Betsi Cadwaladr University Health Board took on the Integrated Mersey Palliative Care Team (IMPACT) model for out of hours care it might not work due to local variation in North Wales compared to Merseyside. She also asked if anybody had walked through the 111 system to test how effective it is for the user and questioned how accurate health board data is?

Tash thanked Ceridwen for her feedback and said it was a good question which they will look into.

Ongoing issues/updates

Mark Isherwood asked members how they would feel if the CPG ran an inquiry into the relationship between hospices and health boards in Wales. Members were generally supportive but **Matthew** said he would need to consult more widely with hospices first and then draft terms of reference for an inquiry.

Members agreed to plan for a hybrid meeting possibly the one after next.

Date for next meeting is Thursday 27th April 2023 at 3.00pm (location tbc)