

GTB Gofal Hosbis a Lliniarol 17 Mawrth 2022, 08.30-09.30  
 CPG Hospice and Palliative Care 17 March 2022, 08.30-09.30  
 Cofnodion | Minutes

Experiences of end of life during the pandemic  
Evidence session 3: A Focus on children and young people

Yn bresennol | Attendance

Mark Isherwood MS	Rhun ap Iorwerth MS
Mike Hedges MS	Heledd Fychan MS
Peredur Owen Griffiths MS	

Lewis Clark, Tŷ Hafan & Tŷ Gobaith	Bethan Edwards, Marie Curie
Dominic Carter, Hospice UK	Ryland Doyle, Mike Hedges MS
Matthew Brindley, Hospice UK	Liz Andrews, City Hospice
Angharad Davies, Tŷ Gobaith	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	
Grant Usmar, Hospice of the Valleys	
Tom Davies, Macmillan Cancer Support	

Ymddiheuriadau | Apologies

John Moss (Welsh Government)	Rachel Williams (Parkisons Cymru)
Melanie Minty (Care Forum Wales)	

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

Mark Isherwood MS opened the meeting and welcomed all, including Hospice UK's new Policy and Advocacy Manager, Matthew Brindley, who will be providing secretariat support to the group going forward. Mark gave special thanks to Lewis Clark from Tŷ Hafan & Tŷ Gobaith who kindly supported the group as secretary for the last two meetings.

Minutes from the previous meeting were confirmed; Tracy Jones proposed, and Peredur Owen Griffiths MS seconded and progress against actions was shared. Following calls from the CPG and members on the Voluntary Hospice Funding Review, the Minister formally announced its findings, providing an additional £2.2m annually to third sector hospices in Wales, including £880k towards Tŷ Hafan and Tŷ Gobaith in the children's sector.

## Ongoing and arising actions

Date	Action
17 <sup>th</sup> 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
17 <sup>th</sup> March	Invite Association of Directors of Social Services and/or a representative from the WLGA to attend a future CPG session to talk about families access to respite

## Deep dive, evidence 3: Experiences of palliative and end of life care in a pandemic – A Focus on Children and Young People

Mark welcomed colleagues from Tŷ Hafan and Tŷ Gobaith children’s hospices to the third evidence session looking at the experiences of end of life during the pandemic focusing on children and young people:

### Setting the Scene, Tracy Jones, Tŷ Hafan

Tracy’s full presentation can be provided as a separate attachment for ease.

Tracy set the scene for the meeting by providing an insight into Tŷ Hafan and Tŷ Gobaith’s Family Voices survey, which centred around two-key questions:

1. What do families with children with life-limiting conditions need to live the best life they can?
2. What role do the children’s hospices in Wales play in providing this support?

Of the 133 respondents, around half outlined they wanted more and longer respite or short break services from the hospice; and 92% stated they had faced financial hardship.

The survey made clear that Tŷ Hafan and Tŷ Gobaith were the families main or only source of respite – with many children the hospices support falling between health and social care, and therefore not being picked up by statutory providers in Wales.



#### • What did the families tell us .....



#### • What did the families tell us .....

- Access to short break care (respite) was essential (94%)
- Hospices were the **only** providers of this respite for 80% of the families
- Access to sibling support, family support, counselling and opportunities to meet other families seen as essential to wellbeing

- Pre pandemic – shrinkage of statutory support
- Interface between health and social care needs
- Less access to appropriate and timely 'respite'
- Leaning into non statutory services
- Social care support focused on safeguarding, assessment and signposting – less about 'keyworking'

- Pandemic magnified the growing disparity between need and available services
  - No school, no respite, disrupted health care packages
  - Isolation and exhaustion
- Increased anxiety and fear of potential death of the child was magnified
  - Families in crisis .....

### Cai's Story, Tracy Jones:

Tracy then read a letter from Micaela, mum of a little boy named Cai who used Tŷ Hafan's services, and sadly passed away in February 2021. Micaela's letter set out how the hospice supported her and her family during Cai's life and throughout his end-of-life care. The letter can be provided upon request.

### Williams Story, Angharad Davies, Tŷ Gobaith:

Angharad Davies, Head of Care at Tŷ Gobaith children's hospice, began her presentation by sharing William's Story with the group:

William was born in the summer of 2018, just three months after Kate's mum had died suddenly of a heart condition. Kate's parents had just sold their home in Spain and were moving back to the UK to spend more time with their family.

Kate had enjoyed a healthy pregnancy and everything seemed to be going according to plan when she went into hospital with her partner Andy to be induced. Tragically, during his birth, William's brain was starved of oxygen and he suffered severe hypoxic brain damage.

William was referred to Tŷ Gobaith by his consultant. Kate had heard of Hope House and Tŷ Gobaith because she had signed up to play our fundraising lottery, but she, like many others, never thought that she would need our help.

During this time Kate's dad Terry had been diagnosed with incurable cancer and was undergoing chemotherapy.

Kate said: "I was able to drop Will off at really short notice and know he was in safe hands. I can't thank them enough for just giving me those precious days so me and my sister Nic could stay with Dad and hold his hand because he was terrified about dying on his own in hospital. I arranged to bring him home for end of life care, and I just couldn't have done that without the support of Tŷ Gobaith."

William's full story can be found on Tŷ Gobaith's website [here](#).

## Supporting a family in crisis



- A family in crisis
- No where else to turn
- Respond at short notice

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hope house tŷ gobaith  
children's hospices

## Hospice Perspective, Angharad Davies:

Angharad shared with the group an insight into Adapting end of life care and therapeutic services during the pandemic.

As the pandemic situation increasingly worsened, and many families cancelled their care packages to stay at home and protect their vulnerable children, Tŷ Gobaith had to adapt to ensure they could continue to be there for them. As a result, the virtual hospice came to fruition.

This allowed the hospice's care teams to provide the same levels of support, and allowed the families to stay at home. Services included:

## Virtual Hospice

- Symptom Control Clinics/ PAC planning
- Welfare calls
- Virtual play and music therapy
- Supporting families in the community
- Crisis and End of Life care
- Physiotherapy Support
- Shielding letters
- Food parcels
- Counselling

23 March, 2022

hope house tŷ gobaith  
children's hospices

Angharad then shared with the group an outline of the two key areas of future service delivery, that came about partly as a result of the pandemic:

# The future of service delivery and lessons learnt

## Key areas of future service delivery

- Key worker project
- Success of Out of hours End of Life service.

## Key Worker Project:

### Key Working:

Research investigating the effects of Key Workers has shown positive results, suggesting that families with Key Workers have better relationships with services, fewer unmet needs, better morale, more information about services, higher parent satisfaction and more parental involvement than families not receiving such a service  
Sloper et al, 2006



### Developing the Service:

- Service led by Deputy Head of Care, supported by a Senior Nurse
- Allocation of Key Workers divided by County
- Funding
- Training
- Vision for the future...



### Impact of Key Working:

- Built positive relationships with families
- Responded to families in crisis
- Signposted to other agencies
- Provided emotional support
- Attended MDTs
- Attended Core Group
- Liaised with school staff
- Re-engaged with families not accessing the hospice
- Facilitated use of 'Cuddle Blanket' and provided memory making opportunities post bereavement



"I can vouch just how amazing your Key Worker service is. N\*\*\*\* is amazing and has the instinct to phone just when you need her. We all have days where we need some advice, guidance or just a chat and **knowing someone is there for just that purpose makes you feel less "guilty" for contacting them.** As you know yourselves us parents and carers will feel we can't bother people and that is exactly what we need to lessen as the sooner we sort an issue, have a chat then as they say **'a problem shared is a problem halved'.**"

## Out of Hours End of Life Project

### Out of hours end of life project

- Preferred place of death; Giving choice!
- Research indicates that the preferred place of death is home where possible
- Provide a 24/7 nursing service to enable a child to die at home in North Wales.
- Partnership working between Betsi Cadwaladr University Health Board and Ty Gobaith Childrens Hospice.
- To enable sharing of knowledge and expertise across the nursing teams.

23 March, 2022



### Impact of Covid on the service

- Clear increase in demand for care at home-preferred place of death.
- Increase in need for step down care from hospital to support symptom management.
- Increase in need for hospice support for nursing and physiotherapy
- Increase in referrals particularly oncology patients
- Established core team for on call support- shared learning and expertise

23 March, 2022



### Feedback from Families

'I think for us, knowing there was a plan put in place at an such an unfamiliar and highly emotional time made the world of difference.'

"Knowing there was an experienced member of the team on hand if/when we needed help and support, gave us the reassurance and peace of mind we needed, which in turn meant we could keep our little boy at home for as long as possible, and as a family that is all we wanted for his end of life care."

23 March, 2022



'After a spell in hospital we came home with our daughter and lots of medication. The nurses explained what it was all for and how to use everything.'

"They also provided us with an out of hour rota organised by Ty Gobaith should we need to access a nurse outside of working hours. Unfortunately our daughter was in the final stages of her life and we needed to call that night. Our wish was to have our daughter at home if she passed away."

"I contacted the team and they came out to our house just after midnight. The nurse was amazing and reassured us, giving us space when we needed it but in the next room if we needed her. She was very calm and kind. I am thankful to have been able to have this support in the middle of the night at home just as we wanted."

23 March, 2022

## Open Discussion & Questions

Peredur Owen Griffiths MS asked whether Ty Gobaith have managed to keep the virtual hospice service going, as the pandemic has eased? And, has this helped the hospice in accessing those hard-to-reach families in more rural parts of Wales?

Peredur also asked, with regards to the Key Worker Project, how much of this service is face to face and how much is virtual?

Angharad Davies: The virtual hospice services are still available, with many accessing a blend of in person and face to face – and this also applies to the key worker project. The virtual hospice project was already in its early stages prior to the pandemic, but kicked on out of necessity.

AD: With regards to the Key Worker Project, this has continued to develop as time has passed. We are now seeing our Key Workers supporting more families in person, e.g. attending hospital appointments, working closely with schools and statutory providers of health and social care.

Mark Isherwood MS (Chair) asked how much the two hospices are designing and delivering services with the Local Health Boards and the Regional Partnership Boards – and what match-funding is made available?

In response, Tracy Jones said: Tŷ Hafan's work with the health boards is very much on a project-to-project basis and while relationships are largely strong, there are concrete or ongoing work plans. With regards to the RPBs – Tracy said that work and engagement is in the early stages but that both hospices are keen to understand how we can be more involved with their work; and look to address some of the concerns around access to respite for children with life-limiting conditions, with many families stating they have struggled to access statutory respite due to confusion over who is responsible for those children with complex, continuing care needs.

Angharad added: Tŷ Gobaith, working with only one Health Board, has a strong relationship with Betsi Cadwalladr – but again, work is on a project-to-project basis. Tŷ Gobaith and Tŷ Hafan are taking a joint approach to working with the RPBs and hope that the move to more integrated working between health and social care will address some of the issues around access to appropriate respite services for children with life-limiting conditions.

Mark asked whether there would be value in a colleague from the Association of Directors of Social Services and/or a representative from the WLGA attending a future CPG Session, in light of some of the issues discussed? The group agreed this would be helpful.

## Ongoing issues and updates

### Welsh Government Update

On behalf of Gareth Hewitt from Welsh Government, Matthew Brindley provided an update on progress in key EOLC policy areas. It was noted that progress had been limited considering it was not long since the last meeting and that they had been dealing with Omicron:

- Phase 2 of the funding review is now currently being scoped and expected to be completed early 2023
- The National Programme Board for End of Life Care is scheduled to come into existence on 1<sup>st</sup> July 2022
- Successful organisations benefitting from the £1m Bereavement Support Grant will be announced on 17<sup>th</sup> March
- The central pause and review of all quality statements, including EOLC, are ongoing

### UK Government Covid-Inquiry

Matt Brindley told the group that the UK Government was now consulting on the terms of reference for its Covid-19 Inquiry. The consultation ends on 7 April. It was noted that deaths at home are currently absent from the terms of reference and that Hospice UK is writing to the Chair of the Inquiry, Baroness Hallett, asking for them to be included.

Mark Isherwood MS suggested that the group draft a submission to Baroness Hallett supporting the call for the increase in deaths at home to be included in the inquiry terms of reference, and write to the Health Minister Eluned Morgan MS raising the same issue and asking for Welsh Government to support. The group agreed to doing this.

Gethin Rhys from Cytun made the observation that the draft terms of reference don't include reference to the voluntary sector and key role it played during the pandemic.

### **Hospice UK Report, Future Vision Cymru – Seamless and Sustainable**

Matt provided a brief summary of Hospice UK's Seamless and Sustainable report looking at the challenges and opportunities facing palliative care in Wales, with a focus on more accessible and coordinated out-of-hours care. Informed by over 80 conversations with people with lived experience and professionals working across Specialist Palliative Care, the report sheds light on three key issues:

- The need to improve out-of-hours care for children and adults dying at home, which was still felt to be something of a postcode lottery
- Importance of key worker and/or a named coordinator roles to act as family liaison and help support people to navigate the system
- Need for a stronger central guiding hand to develop seamless community palliative care in Wales

The report makes a number of recommendations, including:

- Improve knowledge and understanding about taking a whole system approach to 24/7 palliative care across Wales
- Develop a consistent approach to meeting the need for a human single point of access for adults in the community at the end of life
- Improve education, skills-sharing and more joined up local and national thinking across the palliative and end of life health and care system

## **AOB**

Matthew Brindley was formally voted in as the new Secretary of the Cross Party Group. Matthew and Mark to update Senedd Table Office.

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 ends in March.

### **Next meeting dates:**

19 May, 14.30-15.30pm.