

## GTB Gofal Hosbis a Lliniarol 7 Hydref 2021 8:30-9:30yb

## CPG Hospice and Palliative Care 7 October 2021 8:30-9:30am

### Cofnodion | Minutes

### Experiences of end of life during the pandemic

### Evidence session 1: End of life care at home

#### Yn bresennol | Attendance

Mabon ap Gwynfor MS	Peredur Owen Griffiths MS
Jane Dodds MS	Altaf Hussain MS
Rhun ap Iorwerth MS	Mark Isherwood MS

Liz Andrews, City Hospice	Laura Hugman, Paul Sartori Foundation
Lesley Bethell, Compassionate Cymru	Tracy Jones, Ty Hafan
Selena Booth, Magnolia Cancer Charity	Rebecca McDonald, Hywel Dda Paediatric Palliative Care Nurse
Janette Bourne, Cruse Bereavement Care	Trystan Pritchard, St David's Hospice
Dominic Carter, Hospice UK	Gethin Rhys, Cytun
Lewis Clark, Ty Gobaith and Ty Hafan	Katie Reade, Hospice UK
Tom Davies Macmillan	Emma Saysell, St David's Hospice Care
Ryland Doyle (on behalf of Mike Hedges MS)	Glenys Sullivan, St David's Hospice
Bethan Edwards, Marie Curie	Rhys Taylor (on behalf of Jane Dodds MS)
Catrin Edwards, Hospice UK	Anna Tee, Macmillan
Lowri Griffiths, Marie Curie	Grant Usmar, Hospice of the Valleys
Sian Guest, MNDA	Lynne Williams, Covid-19 Families Wales
Deborah Ho, Ty Hafan	

#### Ymddiheuriadau | Apologies

Vikki Evans (on behalf of Jeremy Miles MS)	Mike Hedges MS
Janet Finch-Saunders MS	Darren Millar MS
Andy Goldsmith, Ty Gobaith/Hope House	Iain Mitchell, St Kentigern

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

Mark Isherwood MS opened the meeting and welcomed all, noting that this meeting falls within Hospice Care Week, which is a chance to celebrate the care hospices provide across the country.

Minutes from the previous meeting were confirmed and progress against actions were shared:

- The Minister for Health and Social Services has acknowledged receipt of the previous Senedd CPG inquiry on the role of the Compassionate Cymru programme but has not yet responded to the recommendations. We will seek a response and update the group.
- Catrin Edwards, as Secretary, has received suggestions on the direction of the group's deep dive from member MSs and others. These will be incorporated into the final plan and circulated.
- Mark Isherwood MS, as Chair, wrote to the Chair of the Health and Social Care Committee to inform of the CPG's plans this year. We were asked to respond formally to the Health and Social Care Committee consultation on its priorities. That response was circulated with the papers for this meeting.
- Following the inaugural CPG meeting in July several members supported contributions on the record regarding the hospice funding review, including Dr Altaf Hussain, Jane Dodds and Peredur Owen Griffiths. The hospice sector is grateful for their support.

## Deep dive, evidence 1: experiences of palliative and end of life care in a pandemic – focus on dying at home

### Lowri Griffiths, Head of Policy and Public Affairs, Marie Curie Cymru, 'Better end of life programme'

**Better End of Life Programme**

*Cross Party Group on Hospices and Palliative Care: October 2021*

Lowri Griffiths  
Head of Policy and Public Affairs, Wales



**Aim:** To understand the outcomes and experiences of people affected by death, dying and bereavement in the UK, and to present insights in a clear and persuasive way, compelling policy makers to take action.

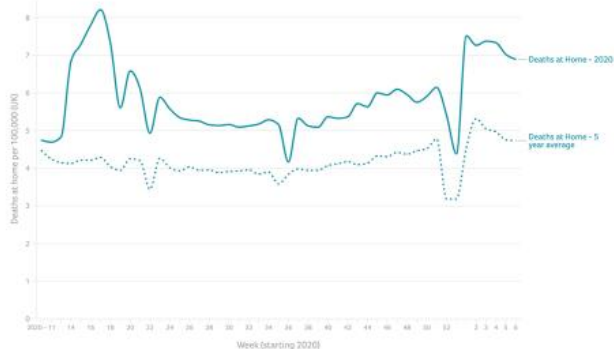
#### The Better End of Life Report

- Explores the ongoing impact of the Covid-19 pandemic on dying, death and bereavement in the UK, so we can learn lessons to inform future policy and practice.
- Independent research by an Expert Group of clinical academics in palliative medicine and primary care from King's College London, Hull York Medical School and the University of Cambridge - with Patient and Public Involvement.
- Draws on published literature, secondary analysis of research data, and analysis of publicly available data.
- **Includes previously unpublished data from the CovPall study, a multinational observational study of palliative care during Covid-19. This includes survey responses PEOLC service providers across all UK nations and English regions.**

#### Individuals experiencing tremendous hardships at an extraordinary time

- One in seven deaths during 2020 was due to Covid-19, the rest due to other causes.
- For people with terminal illness, lockdown and social distancing have caused isolation and loneliness during a phase of life where relationships and human contact are vital.
- Up to 6.2 million people may have been bereaved during Covid-19 and grieving processes have been profoundly disrupted, leaving many at risk of complicated grief.
- **Community care has been over-stretched at the same time as people have been told to 'protect the NHS' and felt discouraged from seeking help at hospital.**

Where people are dying is changing, with many more people dying at home



# Dying at Home

## Recent research findings

## Dying at Home survey, 2021

- Objective: To understand whether people who died at home during the pandemic got the care they needed (includes support for carers)
- Delivered in partnership with Dynata.
- We surveyed 995 bereaved carers across the UK, who had cared for someone at end of life in the last year.



## Topics

### Care received by person who died

- Did the person receive all the health and/or social care and support that they needed during the pandemic before they died?
- Did they get enough support with particular aspects of care?
- What else was needed?

### Support for carers

- Support carers received from health and social care services
- Emotional/physical burdens on carers
- What else was needed?



“ We should not have been made to fight for everything. [We had to make] so many phone calls to different agencies to get things set up in a horrendous crisis time when Dad was deteriorating and needing more support by the week. He was not ill enough for hospital but couldn't walk to the loo or feed himself, we couldn't even lift him and were desperate for help to assist with moving him. Horrendous.



### The pandemic has resulted in a significant increase in the number of people dying at home – what has their experience been?

Our survey found:

- 64% of carers said that the dying person did not get all the help they needed with pain management;
- 61% did not get enough help with personal care; and
- 65% did not get enough out-of-hours support.
- 76% of respondents felt they were not offered all the care and support they needed as carers.
- 78% said the pandemic meant they took on more emotional burdens when caring for the person dying at home.



## Is COVID a glimpse into our future?

We already know that if pre pandemic trends continue by 2040:

- An additional 100,000 people will die in England and Wales each year\*
- The need for palliative care is likely to increase by over 40%\*
- The number of people dying in their own homes will increase by over 80%\*\*
- The number of people dying in care homes will increase by over 100%\*\*

**We need to act NOW to plan to address this demand for the future**

\*Djordjic, S., Bourne, A. et al. 'How many people will need palliative care in 2040? Past trends, future projections and implications for services', *BMC Medicine*, 15 (2017), 2017

\*\*Djordjic, S., Bourne, A., Bourne, B., Djordjic, S. et al. 'What is the impact of population ageing on the future provision of end-of-life care? Population-based projections of place of death', *Palliative Medicine*, 2018, 2018

11  
Care and support  
through terminal illness



## Questions?

Janette Bourne enquired about the studies that project palliative care need into the future. In response, Bethan Edwards shared these in the chat:

<https://bmcmmedicine.biomedcentral.com/track/pdf/10.1186/s12916-017-0860-2.pdf>

<https://journals.sagepub.com/doi/pdf/10.1177/0269216317734435>

References are also included in the slides.

Lesley Bethell said that the pandemic highlighted difficulties people at the end of their lives and their carers face in seeking appropriate support at home but that, crucially, these pressures were present in the system prior to the pandemic.

Selena Booth enquired about the UK and Wales contexts for the Better End of Life programme and research. Lowri confirmed that there were 100 response from Wales out of 1000 across the UK for the Dying at Home survey, meaning that conclusions about experiences from Wales can be extrapolated from the survey. For Wales, lack of access to PPE was a significant feature.

## Lynne Williams, a personal story

Lynne shared her story of caring for her husband Peter in his final months. After a period in an inpatient hospice, during which both Lynne and Peter contracted coronavirus, and visiting was brought to an end, Peter was able to come home. At this point, services were stretched but Lynne and Peter were able to be together, in line with Peter's wishes.

Asked about what changes could be made to help others have a good experience of end of life care at home in the future, Lynne highlighted:

- The importance of maintaining visiting so that people can be with loved ones at the end of life.
  - This was in the context of visiting restrictions to an inpatient hospice and to hospital, which meant that Lynne and Peter were apart for upwards of 5 weeks in his final months.
  - Visits from family who do not live locally should also be permitted. The 'stay local' and 'five mile rule' imposed by the Welsh Government as part of Covid-19 restrictions had particular impacts on people who do not live locally to their

friends and family, making it difficult to make memories with the dying person or to provide support for the carer.

- The importance of aftercare for the carer/loved one. The pandemic has been an isolating experience for all but especially for people who have been bereaved. Good palliative care extends to care for the bereaved person and this should be available to people where the person has died in their own home, regardless of whether there is specialist palliative care involvement or not.

Members of the group thanked Lynne for sharing her story in the chat box.

Janette Bourne noted in the chat that anyone needing support in response to a bereavement can contact Cruse Bereavement Helpline 0808 808 1677.

## Tracy Jones, Ty Hafan, and Rebecca McDonald, Paediatric Palliative Care Nurse Hywel Dda, 'Supporting end of life care at home: a joint approach'

 <p>Supporting end of life care at home A joint approach Rebecca McDonald (Hywel Dda UHB) and Tracy Jones (Ty Hafan)</p>	<h3>Choice of place of care</h3>  <p>Realistic choices for families Hospital/ home/ hospice</p> <p>Current support systems for families choosing home Impact on families Impact on services</p>
<h3>The scenario</h3>  <p>Two families, both supported by local CCN team and known to the hospice, choosing to have their care at home in their local community. Both children 'dying slowly' - unpredictable support needs.</p> <p>How could these families be best supported ..... Team work</p>	<h3>What we did</h3>  <ul style="list-style-type: none"><li><input type="checkbox"/> Joint approach</li><li><input type="checkbox"/> Ty Hafan nurses given temporary Honorary Contracts with the health board</li><li><input type="checkbox"/> Supporting the rota</li><li><input type="checkbox"/> Supporting an 'on call'</li></ul>
<h3>Learning</h3>  <ul style="list-style-type: none"><li>❖ Unpredictability of support needed/ longevity had significant impact on local teams.</li><li>❖ Sporadic nature of EOLC required makes it difficult to plan and deliver desired level of support – family expectations.</li><li>❖ Processes can be expedited if needs are pressing!</li></ul>	<h3>Outcomes</h3>  <ul style="list-style-type: none"><li>✓ Families supported to make confident choices about where and how they wanted their care</li><li>✓ Both children had peaceful, dignified deaths surrounded by family.</li><li>✓ Blueprint for future joint working between local teams and hospice team</li></ul>

Tracy Jones told us about the choices families make about their child's end of life care preferences. For some, the hospice is the right place because they're familiar with the set up

and the professionals. For others, including many who live a significant distance from the hospice, home is the preference.

The workforce providing end of life care for children at home – usually the children’s community nursing team – is small. There is no district nursing service for children as there is for adults. This poses significant challenges for families – in terms of the capacity of the service to provide the care they may want, need or expect – and for the services themselves in terms of the impact on the workforce when a child is approaching end of life.

Rebecca McDonald told us about the end of life care of two children in the Hywel Dda region during Summer 2020. It was unusual to have two children approaching end of life at the same and in the same area. Added to this, the pandemic had an impact both on staffing and on the families, who were shielding and had to make difficult decisions about the care they wanted for their child.

Care was available for the children for five out of seven nights through pooling the workforce, which involved arranging honorary contracts for Ty Hafan nurses with the Health Board (for the first time), drawing on the Hywel Dda COINS (Children’s Outreach Inreach Nursing Service) bank and through agency staff. While there was a significant amount of care for the families, this wasn’t 24 hours, which was felt necessary by one family.

After 12 weeks, families and staff were exhausted. One child was taken to Ty Hafan and cared for at the hospice, surrounded by family, until the end of her life. One child remained at home and was cared for by the community children’s nursing team. Both children had dignified and peaceful deaths.

Learning for the future includes:

- Building in flexibility – each family has its individual needs, which may change over time.
- Build on the model of hospice staff holding honorary contracts with the health board to build capacity in children’s community nursing teams and to enable equitable access to choice of place of death for families.

### **Glenys Sullivan, St David’s Hospice Llandudno, ‘Transforming day therapy to care for people at home’**

Pre-pandemic the hospice had set up an outreach service for people attending day therapy, which would provide symptom management for people in their own homes.

Changes were brought about by the hospice to limit the transmission of Covid-19; these included closing the day therapy service and limiting visitors to the inpatient ward. As a consequence, more people were choosing to be cared for at home at the end of their lives to make it possible to receive visitors.

Multi-disciplinary staff from the day therapy service were therefore deployed to care for people in their own homes in a hospice at home service model. The team consisted of Health Care Workers, Advance Nurse Practitioners and Clinical Nurse Specialists. For people with an Advance Care Plan that identified home as their preferred place of care and death, around 80% of people achieved that preference. Some people were not able to be cared for at home

at the end of life; often this was because they needed a bigger package of support than the hospice was able to provide.

St David's has since received virtual bed funding from the health board, working in partnership to continue delivering the hospice at home service with BCUHB.

## **Discussion**

Jane Dodds MS asked how virtual hospice beds, including for children, are funded, particularly in rural areas.

Tracy Jones responded that Ty Hafan is not commissioned to provide this care by health boards but care is free to families at the point of contact. Ty Hafan, alongside Ty Gobaith, covers all of Wales with an outreach nursing model so families don't have to attend the hospice building. The example given of joint work with Hywel Dda children's community nursing was the first example of putting hospice nurses into the community under an honorary contract with the health board.

Rebecca McDonald added that Hywel Dda maintains the COINS bank to access nurses when they are required. There are education lapses as a result of sporadic need/use of the service. However, the team ensures it works well when needed.

Mark Isherwood MS referred to the [children's hospices Family Voices report](#) and the [CPG Hospices and Palliative Care report on inequalities in access to care \(2018\)](#). The CPG will revisit progress against the recommendations during the course of this year.

Selena Booth noted that successive reports have outlined the changes that are needed and yet there is limited action or progress. Everyone should have access to care at home, including to district nurses, but there is a lack of provision in some regions of Wales. Serious action is needed.

Mark Isherwood agreed and noted that the report on this work will go to the Minister for Health and Social Care and she will be invited to a meeting to give her response.

## **Ongoing issues and updates**

### **Hospice funding review**

Each hospice has had an individual interview with the End of Life Care Board. Health Boards will be invited for a parallel discussion. The review is due to be completed by the end of October 2021, in sufficient time to inform the Welsh Government Draft Budget 2022-23.

### **National Bereavement Framework**

Bereavement has been moved to the portfolio of the Deputy Minister for Mental Health and Wellbeing, Lynne Neagle MS.

We are awaiting the publication of the National Bereavement Framework and the accompanying bereavement funding grant.

### **Next meetings**

13 January 2022, 12-13:30

17 March 2022, 8:30-9:30

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