

GTB Hosbis a Gofal Lliniarol 7 gorffennaf 2022, 12.00-31.30 CPG Hospice and Palliative Care 7 July 2022, 12.00-13.30

Agenda: AGM and a spotlight on deaths at home and poverty at end of life
Cofnodion | Minutes

Yn bresennol | Attendance

Mark Isherwood MS	Heledd Robert (rep Rhun ap Iorwerth MS)
Altaf Hussain MS	Rhys Taylor (rep Jane Dodds MS)
Peredur Owen Griffiths MS	Ryland Doyle (rep Mike Hedges MS)

Ceridwen Hughes, Same But Different	Anna Jones
Dominic Carter, Hospice UK	Karen Owen, Betsi Cadwaladr UHB
Matthew Brindley, Hospice UK	Liz Booyse, City Hospice
Tash Wynne, Marie Curie	Laura Hugman, Paul Sartori Foundation
Tracy Jones, Tŷ Hafan	Anna Tee, Macmillan Cancer Support
Emma Saysell, St David's Hospice Care	Melanie Minty, Care Forum Wales
Janette Bourne, Cruse	Gemma Pontin, Hospice of the Valleys
Grant Usmar, Hospice of the Valleys	James Cooper, Together for Short Lives
Millie Jenkins, MNDA	Lesley Bethell, Compassionate Cymru
Karen Owen, Betsi Cadwaladr UHB	

Ymddiheuriadau | Apologies

John Moss, Compassionate Cymru	Delyth Jewell MS
Idris Baker, National Clinical Lead EOLC	Gethin Rhys, Cytun
Jane Dodds MS	Andy Goldsmith, Ty Gobaith/Hope House

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

Mark welcomed everybody to the AGM, in particular the guest speakers addressing deaths at home and poverty at end of life. He noted that these areas are of particular importance for the future work of the CPG considering the inquiry into experiences of end of life during the pandemic is drawing to a close.

Mark congratulated Liz Booyse from City Hospice on her election as the new Chair of Hospices Cymru and thanked Trystan for the amazing job he has done as Hospices Cymru Chair over the last four years, especially through the challenges of Covid.

Minutes from the previous meeting were confirmed by Tracy Jones and seconded by Janette Bourne. Mark updated members on progress against actions:

- Wrote to the Chair of the UK Covid 19 Inquiry, Baroness Hallett, inviting her to the AGM to provide an update on how deaths at home and Wales-specific issues and experiences will be included within the scope of the Inquiry. Her team said it would not currently be appropriate to meet with individual Members of Parliament, or their groups or committees, to discuss the Inquiry's work before it's formally established by the Prime Minister.
- Wrote to the president of the Association of Director of Social Services Cymru about improving access to short breaks for children with life-limiting conditions and their families. They confirmed they are happy to speak to the CPG on this issue and will attend next meeting after the recess.
- Analysis of evidence submitted to the inquiry into experiences of end of life during the pandemic is ongoing and initial findings will be circulated to members over the summer.

Ongoing and arising actions

Date	Action	Status
17 th 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	Complete
17 th March	Invite Association of Directors of Social Services and/or a representative from the WLGA to attend a future CPG session to talk about family access to respite	Wrote to them with positive response: send date and invite for next meeting
7 th July	Circulate initial inquiry findings to CPG members for feedback over the summer	
7 th July	Write to Health Minister highlighting issues raised in Ceri's presentation and progress against recommendations in CPG report into inequalities in access to hospice and palliative care	
7 th July	Write to Betsi Cadwaladr UHB highlighting Ceri's experience and ask what the HB can do to improve these issues	
7 th July	Ask Hospices Cymru members how they can work together with Health Boards to address the issues Ceri raised	
7 th July	Set and circulate dates for CPG meetings in 2022-23	

Annual General Meeting: Election of Chair and Secretary

Mark noted some of the highlights of the CPGs work over the last year from the Annual Report and Financial Statement:

- Welsh Government accepted all four top level recommendations on the role of the Compassionate Cymru programme in building capacity and resilience within the community.

- The UK Covid 19 Inquiry supported the CPG, and Hospice UK coalition calls, for deaths at home to be included in the Inquiry terms of reference. This followed the CPG writing to the Health Minister and securing the support of the First Minister on this issue.
- The CPG conducted a detailed inquiry into experiences of palliative and end of life care during the pandemic involving evidence from over 50 stakeholders, including people with lived experience and those working across hospice and palliative care (the inquiry report is due to be published towards the end of the summer).
- The CPG continues to be an active and inclusive forum bringing together people with lived experience, clinical and community expertise, and policy and research knowledge to improve palliative and end of life care for everybody in Wales.

Mark Isherwood MS stepped down as Chair.

Peredur Owen Griffiths MS nominated Mark Isherwood to be re-elected to Chair and was seconded by Altaf Hussain MS and Matthew Brindley.

Mark Isherwood was duly elected as Chair of the CPG Hospices and Palliative Care for 2022/23.

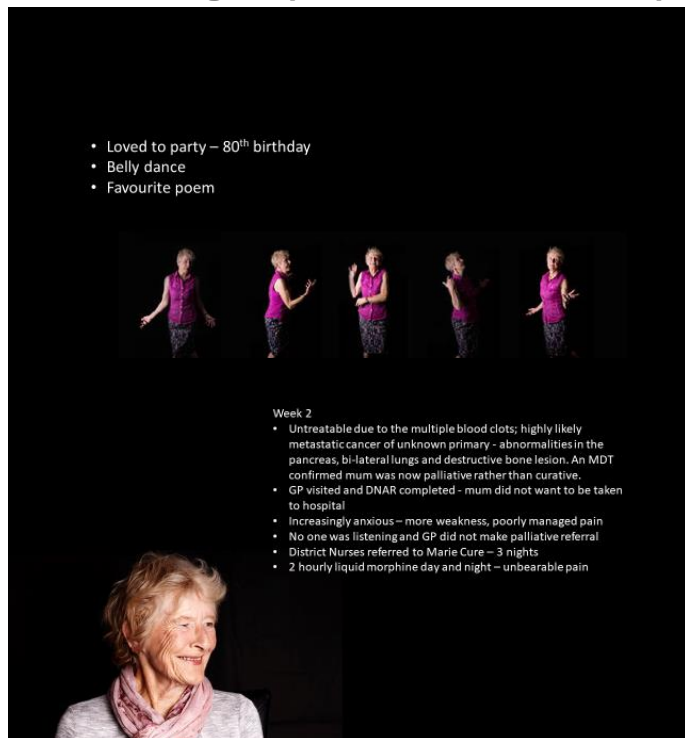
Matthew Brindley stepped down as Secretary. Altaf Hussain MS nominated Matthew Brindley on behalf of Hospice UK to provide Secretariat. Seconded by Tracy Jones, Mark Isherwood and Peredur Owen Griffiths MS.

Matthew Brindley elected as Secretary for 2022/23.

Spotlight on deaths at home

Mark welcomed Ceridwen Hughes from the Same But Different to talk about her and her sisters experience of caring for their mother at home at the end of her life.

Ceridwen Hughes presentation on lived experience of dying at home – slides



- Loved to party – 80th birthday
- Belly dance
- Favourite poem

Week 2

- Untreatable due to the multiple blood clots: highly likely metastatic cancer of unknown primary - abnormalities in the pancreas, bi-lateral lungs and destructive bone lesion. An MDT confirmed mum was now palliative rather than curative.
- GP visited and DNAR completed - mum did not want to be taken to hospital
- Increasingly anxious – more weakness, poorly managed pain
- No one was listening and GP did not make palliative referral
- District Nurses referred to Marie Cure – 3 nights
- 2 hourly liquid morphine day and night – unbearable pain



Week 1

- March 2020 – returned from Turkey
- Had a stroke
- carotid artery was 80-95% blocked
- Multiple blood clots
- CT and MRI - probable malignancy in pancreas and both lungs
- Previous hip surgery - no benefit in terms of pain relief from morphine
- Still prescribed morphine and Zapain
- 9/10 pain – urinate mop bucket

Week 3

- Living nightmare – pain changed - much more bone pain, particularly in her upper thigh
- Online farewell party for mum to say goodbye to her friends
- 2nd April – no longer able to swallow 12/10 despite 95mg oral morphine throughout the day
- Urgent response – Sub Cutaneous STAT dose of Morphine and Midazolam
- syringe driver with considerably higher doses as she needed 5 visits from DN's to give additional STAT doses in a 24-hour period
- Mobile phone and landline phone show that a total of 43 phone calls were made to a combination of GP, Out of Hours, Palliative Care and District Nurses over a 3-day period (2nd, 3rd & 4th April) – not one home visit by GP
- "What do you want me to do about it? Call the District Nurses".
- Paramedics called because unable to get through 40 mins to OOH – full answer phone
- Finally new GP and Palliative care – changed med



Mark thanked Ceri for speaking so clearly and affectionately about her mother who sounded like an amazing woman. He welcomed Dom from Hospice UK.

Dom Carter presentation on wider policy context of deaths at home – slides



- 85% hospice care now delivered in the community (90% for adults in Wales)
- Growing range of services within the home and community, under a variety of names and definitions
- Community palliative care can help prevent hospital admissions among people near the end of life
- Hospitals under pressure for a considerable period, with backlog in routine work

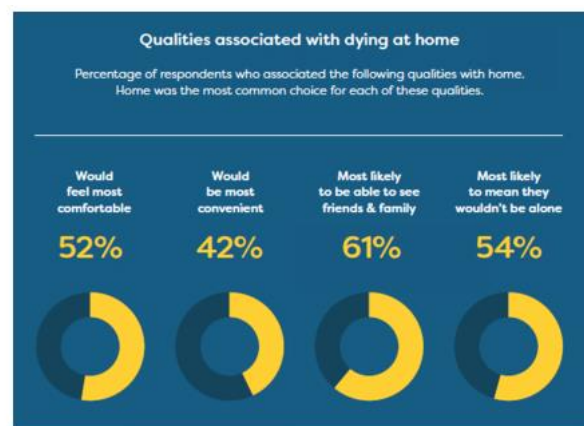


www.hospiceuk.org

Excess deaths at home

- 110,000 excess deaths at home since March '20 (UK)
- 5000+ deaths at home in 2022 (Wales), 30% of all deaths
- Avg of 209 a week similar to 2020 (225) and 2021 (214)
- 2.5% home deaths from covid-19 (2020-2021)
- 60% of hospital death numbers and twice as many as care homes

www.hospiceuk.org



www.hospiceuk.org

COVID-19 turbocharged innovation

- Rapid adoption of technology
- Expanded or redeployed staff, with integrated working
- Extended hours or new approaches to 24/7 care
- Advances in anticipatory prescribing, changes to triaging and new approaches to MDT working
- Swift training of staff on verification of death and medication

www.hospiceuk.org



Where do we look in the future?

1. Covid-19 inquiry to have death at home as a focus
2. Skills, training and confidence of generalist workforce
3. Reassess and reconfigure community capacity, backed with funding and resource
4. Carve out space for learning and reflection
5. Care at home to get equal prioritisation of in-hospital treatment

www.hospiceuk.org



Mark thanked both Dom and Ceri for their presentations and opened for comments and questions.

Liz Booyse thanked Ceri for being so brave, said her Mum sounded like a beautiful person and that her experience was really valued and would help create change.

Lesley Bethell thanked Ceri and said she was sorry for her loss and that sadly she is still hearing from others with very similar experiences, many of whom are not as well placed as Ceri and her family to speak out. She commented that Ceri had previously presented to the End of Life Board but little has changed since then.

Ceri said she had hoped her experience was a rare occurrence but she's met many people with similar experiences, including another example of a woman not being referred to palliative care. She said that palliative care education across the wider health service is essential.

Anna Tee thanked Ceri and said they had heard similar stories before and that we all have to work together to create change.

Emma Saysell asked Ceri if she felt there had been any change since speaking to the End of Life Board, considering a lot of the issues raised are fixable. Ceri said she had never heard anything from Betsi Cadwaladr after they saw her presentation to the End of Life Board. She never made a formal complaint because her motivation was to improve palliative care for others. Things haven't changed in her experience and the move to 111 from out of hours may have made things worse. Lesley Bethell said she also raised Ceri's case with Betsi and had no response.

Tash Wynne said they had heard stories like Ceri's time and time again and there is a gap in strategic direction that needs to be addressed with the new end of life quality statement.

Ceri commented that Betsi Cadwaladr had stopped doing palliative care at the weekend and that we need to move beyond words on paper/policy as it doesn't always have an impact on the ground. We need to make sure people's stories are being told as this can be an effective way of creating change. Mark Isherwood clarified that the cancellation of palliative care at the weekend by Betsi Cadwaladr only applied to media reports of one weekend and that Nightingale House Hospice had filled the gap that weekend.

Altaf Hussain MS said we need to raise this with the Health Minister flagging ethics and human rights issues. He said GPs, DNs and others in the health service need training in palliative care and we need better out of hours support.

Karen Owen said she would chase up with colleagues in Betsi Cadwaladr to help address the issues Ceri raised.

Mark asked how hospices in Wales could work together with Health Boards to address the issues Ceri raised and create positive change? He also asked Ceri and the group about writing to the Health Minister and Betsi Cadwaladr, which they supported.

Emma Saysell and Lesley Bethell said that we need to look at areas of good practice, understand what works and replicate it across Wales. Lesley placed emphasis on implementing policy, including some of the ambitions in the new quality statement.

Spotlight on poverty at end of life

Mark noted that poverty at end of life is another hugely important issue which is having an ever growing impact on the end of life experiences of people across Wales. He welcomed Gemma Pontin, Welfare Rights Advisor for Hospice of the Valleys in Blaenau Gwent to speak about her experiences supporting people at end of life in the cost of living crisis.

Gemma Pontin presentation on experiences of supporting people at end of life in the cost of living crisis – speaking notes

Thank you for giving me the opportunity to speak today. I joined the hospice this year in April as a welfare rights adviser.

Previously I had worked in the DWP for 24 years. I wanted a role where I was supporting people as opposed to hindering.

In the short time I have been seeing patients one of the main concerns is finance, and this is one of the main priorities after diagnosis.

The majority of patients have previously worked and find themselves in a situation that they had not foreseen, having to navigate the complexities of the benefit system.

I did ask if any of the cases I am about to talk to you about, were willing to speak today, unfortunately they wouldn't, when speaking about finance and benefits many feel shame and embarrassment.

It needs to be acknowledged that Blaenau Gwent, where the Hospice of the Valleys is based, is one of the most deprived areas in UK and even Europe.

Nearly four in 10 households in Wales do not have enough money to buy anything beyond everyday items, according to a report by The Bevan Foundation, and this situation is likely to get worse as the cost of electricity, gas, fuel and food increases.

Before Covid arrived, Wales already had the highest poverty rates of all the UK. Four of Gwent's council areas are among the most deprived: Blaenau Gwent is currently the highest, with this in mind you can appreciate the enormity of the cost of living crisis on our patients.

I'm about to tell you of three cases, all of whom I have been working with since April this year.

Case 1

Thelma is 58 and the main carer and appointee for her disabled daughter. She also has guardianship of a grandson aged 9. Thelma is claiming Universal credit and currently receiving treatment. The treatment leaves her with extreme pins and needles. She was advised to keep warm, put the heating on, this would ease her side effect symptoms. Unfortunately this is not an option, instead Thelma got some hot water bottles as it was all she could manage. She couldn't afford extra heating costs, she is all too aware she has her grandson home from school shortly for 6 weeks holidays and that extra food will be needed whilst he is not getting school dinners.

Case 2

Karl's wife is terminally ill, he is currently off work, and he has exhausted all his full sick pay with the employer and is now receiving Employment Support Allowance from DWP. He now receives £77 a week, a substantial drop in income where he previously earned £21,000 a year. Karl is not eligible for any mean tested benefits therefore will not be eligible for any cost of living support from DWP. Karl has used all his savings and is now living on credit cards. He feels so embarrassed and cannot reveal to his wife the amount of debt. Karl states he would take his wife to the end of the earth, if he thought he could help her and ease her pain. Fuel costs are crippling him, every time they have a hospital appointment it is a 70 mile round trip costing more than 1 week's benefits. They cannot claim costs from the hospital due to not being on mean tested benefits. My last meeting with Karl he was extremely upset, he said every time he used the credit card to get fuel he prays he has enough credit. He wants to take his wife to all the appointments, he feels that is his role, however, he doesn't know how long this can be sustained.

Case 3

David is a carer for his dad and his wife is self-employed with little income. David no longer drives, nor does his wife or immediate family. David was called on Monday to be in hospital for Wednesday for major op. After the call from the hospital, David's wife immediately contacted hospital transport. David's wife was instantaneously told all requests had to be within 48 hours and their request was 47 hours. Both were desperate to get David to hospital for the planned operation. With no options that they could

foresee they paid £100 for a taxi from home to the hospital, using all of David's wife's week's earnings, leaving the couple with nothing.

As you just heard all 3 cases are very different all with a common theme, cost of living severely impacting the precious time end of life patients have.

Mark thanked Gemma and welcomed Tash Wynne, Research and Policy Manager for Marie Curie Wales to talk about Marie Curie's recently published research into Dying in Poverty.

Tash Wynne presentation on Dying in Poverty research – slides

Dying in Poverty

Examining the cost of dying crisis in Wales

In the next 10 minutes...

1. What we already knew
2. Findings from Loughborough University research
3. The costs of dying in a cost of living crisis
4. How can we stop people dying in poverty in Wales?

Hospices and Palliative Care CPG, 7th July 2022

Natasha Wynne, Research & Policy Manager, Marie Curie Cymru
Natasha.Wynne1@mariecurie.org.uk



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Care and support through terminal illness



What we already knew

- Wales has the highest poverty rate of all UK nations
 - Pre-pandemic, 700,000 living in poverty (1)
 - Well-documented link between poverty and ill health
 - Cost of terminal illness: £12,000–£16,000 per year (2)
- But...**
- Not clear how many people die experiencing poverty, or
 - Which groups are most at risk?

(1) JRF (2020) Poverty in Wales 2020
(2) Marie Curie (2019) The cost of dying

3
Care and support through terminal illness



Findings from Loughborough University research

- People in Wales are more likely to experience poverty at the end of life than in any other UK nation
- In 2019, more than 6,600 died in poverty
- Working age almost twice as likely to die in poverty

	Working age (20-64) in last year of life		Pensioners (65+) in last year of life	
	Number	%	Number	%
Wales	1,512	30.4%	5,148	18.4%
England	19,848	27.5%	55,724	13.3%
Scotland	2,801	26.5%	5,746	12.2%
Northern Ireland	699	25.7%	1,334	10.4%

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Care and support through terminal illness



Findings from Loughborough University research

- People with a terminal illness significantly more likely to experience poverty than the general population

	Last year of life		Not last year of life	
	Number	%	Number	%
Working age	1,512	30.4%	421,203	23%
Pensioners	5,148	18.4%	91,161	15.1%

- Risk factors for dying in poverty:
 - Working age with dependent children
 - Place of residence – people in Cardiff, Newport, Blaenau Gwent and Swansea have highest risk
 - Women
 - People from ethnic minority groups



The costs of dying in a cost of living crisis

“ I have lung cancer on immunotherapy, to give me longer hopefully but cannot be cured.

I am not putting on heating, using blankets to keep warm.

Not eating as well as I should as food is so expensive.



The costs of dying in a cost of living crisis

“ My mum is at her end of life and struggling to make end meet...

Had to cancel carers and now her daughters are looking after her full time



The costs of dying in a cost of living crisis

“ I have stage IV breast cancer, I'm unable to work and rely on benefits.

Food, travel, clothing have all massively increased - my benefits haven't.



How can we stop people dying in poverty?

<p>Welsh Gov:</p> <ul style="list-style-type: none"> • Extend eligibility criteria of the Nest Warm Homes scheme to ensure terminally ill people can access timely support • Ensure HCPs are signposting to welfare benefits advice 	<p>Local authorities:</p> <ul style="list-style-type: none"> • Review eligibility for Council Tax Reduction Scheme • Prioritise people with terminal illness for Discretionary Housing Payments • Encourage compliance with NICE NG6 through RPBs 	<p>Employers:</p> <ul style="list-style-type: none"> • Support employees with a terminal illness to continue working if they wish • Do not dismiss any employee with a terminal illness because of their condition 	<p>UK Gov:</p> <ul style="list-style-type: none"> • Facilitate access to pension entitlements for people of working age • Additional support for childcare costs through UC • Winter fuel payments for under 65s • ...
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Find out more

1. The full research report from the Centre for Research in Social Policy, Poverty at the end of life in the UK, can be read here: mariecurie.org.uk/povertyatendoflifeintheuk
2. The full Marie Curie policy report, Dying in Poverty, can be read here: mariecurie.org.uk/dyinginpoverty
3. The short briefing outlining the implications of the research for Wales can be read [here](#)



Mark thanked Tash and Gemma and opened for questions. He noted that as Chair of the CPG on Fuel Poverty and Energy Efficiency he would be interested in raising some of these issues in their meeting with Minister Jane Hutt MS. He asked Tash if Marie Curie had presented their report to the Government. Tash said they hadn't but intended to.

Altaf Hussain MS commented that some areas of entrenched poverty in Wales haven't changed despite EU and WG investment over the years. He said a different approach was needed to addressing poverty.

Mark suggested the CPG could write to the WLGA, DWP and other relevant bodies if it's helpful and could return to this issue at a future meeting.

Ongoing issues/updates

Matthew provided a brief update on key WG policy developments and the CPG inquiry into experiences of end of life during the pandemic:

- The Quality Statement for Palliative and End of Life Care (high level WG policy document setting standards and expectations) is now nearing completion, subject to final feedback from users groups. Publication is expected towards the end of the summer.
- The launch of the new National Programme Board for Palliative and End of Life Care (replacing the previous End of Life Board which had its last meeting in July) has been delayed and is now looking like September. It was supposed to launch in July but WG are reviewing the terms of reference for the board.
- No new update on the phase two funding review since Idris Baker spoke to the CPG in May. The deadline for completing the review remains January 2023. It's ambitions remain broad, including completing research on population needs assessment, workforce, primary care and social care by August that will help inform the review

Matthew also provided an update on the CPG inquiry into experiences of end of life during the pandemic. He thanked everybody who contributed and confirmed the inquiry had received over fifty responses which were now being analysed. He hoped to be able to circulate a draft document with initial findings and recommendations for feedback from members over the summer.

Matthew said the spotlight on deaths at home and poverty at end of life were intended to get the group thinking about future priorities for CPG over the next year which he hoped could be discussed at the next meeting.

Mark said dates for meetings for 2022-23 will be set and circulated to members and asked Matthew to arrange with his office.