

GTB Hosbis a Gofal Lliniarol 13 Gorffennaf 2023, 3.00-4.30pm
 CPG Hospice and Palliative Care 13 July 2023, 3.00-4.30pm

AGM, inquiry into the future of hospice care in Wales and spotlight on Advance Care Planning

Cofnodion | Minutes

Yn bresennol | Attendance

Mark Isherwood MS	Will Davies (Rhys ab Owen MS)
Emily Hearne (David Rees MS)	

Fay Morley, Paul Sartori Hospice at Home	Emma Saysell, St David's Hospice Care
Dominic Carter, Hospice UK	Catrin Glyn, Carers Trust Wales
Matthew Brindley, Hospice UK	Tina Ahang, Together for Short Lives
Tracy Jones, Tŷ Hafan	Laura Hugman, Paul Sartori Hospice at Home
Miranda McGinn, City Hospice	Prof. Mark Taubert
Ellen Greer, St Kentigern Hospice	Mary Mitchell
John Moss, Compassionate Cymru	Gethin Rhys, Cytûn Churches Together in Wales
Grant Usmar, Hospice of the Valleys	Huw Owen, Ty Gobaith/Ty Hafan
Jenny-Anne Bishop OBE, Unique Transgender Network	Liz Booyse, City Hospice

Ymddiheuriadau | Apologies

Altaf Hussain MS	Jane Dodds MS
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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 Liz Booyse.

Mark updated members on progress against actions:

- Wrote to the Minister for Social Justice, Minister for Health and Social Services and the National Programme Board for Palliative and End of Life care asking what Welsh

Government is doing to improve care for trans and gender diverse people and sharing the Hospice UK report 'I Just Want to be Me'.

- Followed up on recommendations from last inquiry and wrote to Health Education and Improvement Wales and Social Care Wales asking how their 10 year workforce strategy will address the future staffing requirements and education and training needs of all those working across palliative and end of life care. Will also shortly be writing to all Health Boards in Wales to ask them to respond to the recommendations in the inquiry report.
- Disappointingly, despite numerous attempts, the Association of Directors of Social Services have not meaningfully engaged with either the CPG or the children's hospices to discuss improving partnership work on access to short breaks for children with life-limiting conditions and their families. Plan to write to their president to raise concerns regarding this lack of engagement.
- Have sent the CPG inquiry report into experiences of palliative and end-of-life care in the community during the pandemic to the UK Covid-19 Inquiry and remain in contact with Anna-Louise Marsh-Rees from Covid-19 Bereaved Families for Justice Cymru regarding submitting evidence to module 3 of the UK inquiry and to the new Senedd Covid-19 Committee.

Ongoing and arising actions

Date	Action	Status
13 th July	CPG to write to the Minister for Health and Social Services regarding challenges Welsh hospices are facing	Ongoing
13 th July	CPG to work with Hospice UK to better understand variations in statutory hospice funding across the UK and within Wales	Ongoing
27 th April	CPG to 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 (send CPG inquiry report to new committee via Altaf Hussain MS)	Ongoing
26 th Jan	Share CPG inquiry report with Health Boards	Ongoing
27 th Oct	Write to the President of the Association of Directors of Social Services Cymru on improving family access to respite.	Ongoing

Annual General Meeting

Mark Isherwood noted some of the highlights of the CPGs work over the last year:

- Published CPG inquiry report into experiences of palliative and end-of-life care in the community during the pandemic resulting in full Senedd debate with 9 members from all the main parties participating and Welsh Government accepting the key recommendations in the report.

- 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 in Wales
- The CPG has kept hospice, palliative and end of life care issues on the agenda writing regularly to and engaging with Welsh Government, UK Government, UK COVID-19 Inquiry, Health Boards, and various government bodies advocating for policy and funding solutions to support and develop a more sustainable sector and address inequalities.
- Secured the inclusion of hospice staff in the Canopi mental health support service for NHS and social care workers (they were previously not eligible) through CPG contact with its Director.

Mark Isherwood MS stepped down as Chair.

Liz Booyse nominated Mark Isherwood to be re-elected to Chair and was seconded by Tracy Jones and Matthew Brindley.

Mark Isherwood was duly elected as Chair of the CPG on Hospice and Palliative Care for 2023/24.

Matthew Brindley stepped down as Secretary. Mark Isherwood nominated Matthew Brindley on behalf of Hospice UK to provide Secretariat. Seconded by Liz Booyse and Natash Wynne.

Matthew Brindley elected as Secretary for 2023/24.

CPG inquiry into the future of hospice care in Wales: Challenges facing hospice services:

Rachel Jones, Associate Director Wales, Marie Curie presented to the group on the services Marie Curie deliver across Wales and some of the pressures and challenges they are currently facing. She highlighted the reduced capacity they have due to staffing and financial pressures.

Marie Curie are aligned to Agenda for Change pay scales and the huge increases to wage bills are not necessarily being passed on by Welsh Government and Health Boards. So far only two Health Boards have confirmed uplifts to their services, despite WG writing to advise them to do so, reflecting the lack of consistency in funding arrangements across different Health Boards.

Rachel gave an example of funding negotiations with one Health Board who said there's no money and suggested stopping the contract at 9 months, which would result in those receiving care and support from Marie Curie being dropped as well.

There is a lack of understanding and recognition within Government of what hospices do and the how they contribute to wider health and social care services. Needs to be a real change in how WG view and value hospices to fully recognise and value them as essential partners in delivering palliative and end of life care to people in Wales.

SLIDES BELOW



1

In 2022/23 we supported 3,070+ people...

Hospice@Home / Nursing Service	<ul style="list-style-type: none"> Delivered across 6 Health Board areas Mixture of 24 hour care, overnight services, out of hours rapid response and dementia support 2,285 patients supported through 27,215 visits and delivering 132,125 hours of care. Average number of visits per patient was 11.9
Vale of Glamorgan Community Specialist Palliative Care	<ul style="list-style-type: none"> 537 individual patients supported through 1,638 visits and 6,742 telephone consultations
Cardiff & Vale Hospice Inpatient Unit	<ul style="list-style-type: none"> 248 individual patients cared for with an average length of stay as 16.4 days.

2

We also deliver support through...

Well-being and Support Hub	<ul style="list-style-type: none"> Re-established within Hospice in 2023 Offers dementia support sessions, carer's café, complementary therapies etc Non-commissioned service
Wales Bereavement Information & Support Service (BISS)	<ul style="list-style-type: none"> Provision of Bereavement Counselling Group Support Volunteer Telephone Support Volunteer Companions Development of accessible Information Delivered in partnership with Diverse Cymru Part-funded by WG Bereavement Framework Grant
Volunteer Companion Services	<ul style="list-style-type: none"> Operates in 5 health board areas (2 grant funded) Befriending and Emotional support Practical help Signposting Postbereavement support

3

Issues we are facing...

- Recruitment and retention** – alignment to AfC
- Rising costs** – salaries, utilities, supplies, maintenance, service charges, mileage costs
- Huge effort negotiating uplifts**
- Varying contract holders**
- Protracted procurement exercises**
- Demand is increasing** - but resources are reducing = service reductions in some areas

4

Issues we are facing...

- Lack of appreciation of charitable contribution**
- Lack of understanding of regulatory requirements (CIW and HIW)**
- Short-term grant funding**
- Challenging fundraising environment**
- Recruitment of volunteers**

5

Issues we are facing...

- Lack of integrated funding** - across health, social care and Regional Partnership Boards
- Limited (or no) access to WG funding** - Regional Integrated Fund, Winter pressures funding (508 extra community beds) or Building Community Capacity (Further Faster)
- Hospice Funding Review** – Phase 2 wasn't collaborative and didn't address recommendations
 - Unlikely any meaningful service specification by Autumn
 - Needs collective discussions not silo conversations
- Keeping the lights on Monday – Friday!**

6

What is needed?

- Clearer **instruction** from WG to LHBs regarding uplifts on an ongoing basis
- Recognition** that Inpatient Units and Hospice@Home provide community capacity to prevent admissions to hospital or provide step down
- GENUINE** collaborative discussions on an **equal basis** between statutory and third sector providers to agree specification for PEOLC at both a national and LHB/RPB footprint and the service levels required to meet population need
- Greater emphasis on understanding key provision which is **not specialist palliative care** but has huge impact on delivering positive outcomes for families
- Integration** of funding to support PEOLC

7

What we can't forget...

Feedback from Daughter of a patient who received our nursing care:

"Our Dad was taken from us too soon, on the 22nd of February 2023, aged just 65. It is heart-breaking to lose Dad to cancer, but we take comfort in the fact that he was able to pass away at home with us [family] by his side. That wouldn't have been possible without Marie Curie.

The dignity and respect in which they carried out their roles was as remarkable as their compassion; they allowed Dad to feel comfortable and dignified - That means the world to us. Marie Curie were there to support us as a family too and always had a cwch to hand when needed. We can't thank them enough"

8

Andy Goldsmith, CEO of Ty Gobaith/Hope House Children's Hospices and Tracy Jones, Director of Family Wellbeing and Outreach Services with Ty Hafan summarised the latest data on trends in prevalence and complexity for children in Wales requiring palliative care and outlined some of challenges hospices face delivering this care.

Tracy and Andy talked about the challenges delivering services to meet a small local need across large areas of Wales where hospices are often the only source of support for children and their families. Cost of travel continues to be a real challenge for families alongside out of hours support and partnership work with increasingly overstretched children's community nursing teams. Despite these challenges children's hospices continue to play a key role providing care closer to home, with all community hospice nurses in Wales being charitably funded.

They highlighted the need for a sustained increase in paediatric nurses and community nursing services which can only be met in partnership with Health Boards and Welsh Government. Hospices need to be treated as equal partners in this process and there is need for a Wales wide plan to recruit in paediatric care.

SLIDES BELOW

Meeting needs for children with life limiting conditions in Wales

Some challenges facing Wales's children's hospices

Tracy Jones: Director of Family Wellbeing and Outreach Services. Tŷ Hafan Childrens Hospice
 Andy Goldsmith: Chief Executive, Hope House and Ty Gobaith Children's Hospices

1

2

The number of children with life limiting conditions is increasing

- 3655 babies and children with a life limiting condition in 2019 an increase of almost 25% over the decade.
- Greatest increase in the under 1 year

3

104 children with a life limiting condition died in 2019

Over 50% of children who died in 2019 had an underlying life limiting condition.

This percentage rose to almost 70% of children aged 5-11 years who died.

Majority of deaths are babies under 27 days followed by young adults aged 18-25 years

4

Children with a life limiting condition are resident across Wales

Higher prevalence in areas of deprivation

5



Reaching every child and care closer to home

- Many children live over 2 hours drive from the hospices
- Under resourced Community Children's Nursing Teams
- Evening and weekend cover delivered by goodwill
- Phase 2 recommendation to increase funding for Clinical Nurse Specialists and District Nursing Teams-Adult only. **No funding for children's services...**
- **'The intention is to include this in phase 3 report, Programme Board Minutes June 2022'**

6

Children's Hospices- Outreach

- Recruiting hospice and children's nurses to work in the community
- Embedding staff within Community Children's Nursing Teams
- Increased outreach and community engagement activity
 - Hubs
 - Drop in 'clinics'
 - Tele health and video conferencing
 - Key workers
 - Community Engagement Workers – raising awareness
 - Joint working with other locally based charities

7

Children's hospices outreach -challenges

- Dialogue with Health Boards on joint solutions can be challenging
 - Workforce sharing agreements – all different and locally negotiated
 - Risk adverse-avoidability
- Community hospice nurses all charitably funded – sustainable funding
- Workforce shortages
 - Despite increases over the past decade, Wales and Northern Ireland's nursing workforce remains under significant strain – even 'crisis point'²¹ While measures such as upskilling and retention are important, a sustained increase in these numbers is required.
 - While children's nursing in hospitals has grown in the last decade, the opposite is true of their counterparts in the community. Future investment in workforce should mirror the changing focus of care for children and young people, moving from hospitals to the community, and from care delivered by a single institution to a more integrated approach that crosses organisational boundaries. ²²State of Child Health in the UK 2020: Royal College of Paediatrics and Child Health




8

Grant Usmar highlighted that the challenges Rachel described are being experienced by many hospices in Wales. He asked Andy and Tracy if there was nervousness among nurses to leave the NHS for hospices?

Andy said that the reality is that there just aren't the staff out there and **Tracy** said that nurses can pick and choose jobs at the moment.

Dom Carter asked how the children's hospices are planning to meet the population need identified in the prevalence study?

Andy highlighted that not all the 3655 babies and children identified in the study will need or want hospice services at any given time and that their focus is on looking at who is currently being missed by children's hospices services. Tracy said that a key means of addressing inequalities in access to care is looking at how nurses can be embedded in local communities to better understand and meet local need.

Mark Isherwood described how there was lower awareness and access to services among non-white communities and **Andy** agreed that they don't currently fully understand the reasons why non-white people have lower engagement with services and that this is a key focus of their work.

Mark Isherwood asked what Hospice UK is doing to better understand variations in statutory hospice funding across the UK and within Wales and said he would like to look at this in more detail.

Matthew Brindley said Hospice UK will be publishing an updated Hospice Accounts report in the coming months which would provide up-to-date data on hospice statutory funding across the UK and within Wales. Dom Carter described a finance benchmarking survey currently being conducted by Hospice UK which could also help better understand the breakdown of charitable and statutory funding for hospices.

Liz Booyse, Chair of Hospices Cymru thanked Rachel, Tracy and Andy for sharing their experiences and described the wider challenges facing Hospices Cymru members and the work they are doing engaging Welsh Government to address this. She welcomed the Health Minister's commitment to strengthen specialist palliative care and the recognition that these services are 'absolutely crucial'.

Hospices Cymru members are committed to being efficient and provide exceptional value for money to the wider health and social care system with only a third of their costs being met by statutory funding, and the remainder coming from the support of communities, who fundraise, make donations and shop in charity stores.

However, the harsh reality is that due to the economic crisis, and the challenging staff recruitment and retention market, the majority of hospices will make significant losses this year and will report large deficits. In the short term, some will meet these additional costs through cutting services, pausing development programmes, and others will utilise their reserves. This is not sustainable.

Phase 3 funding review is critical in helping address these short and medium term challenges and it is essential that the Health Minister meets her commitments to consider inflationary uplifts, staff retention, the agenda for change costs and the duration of service level agreements.

Spotlight on Advance Care Planning

Mark Isherwood reminded members that the last CPG inquiry recommended that Welsh Government should, as a matter of urgency, develop an electronic patient record with Advance and Future Care preferences and decisions and welcomed the opportunity to revisit this issue.

Laura Hugman and **Fay Morley** from Paul Sartori Hospice at Home presented to the CPG on their experience delivering a nurse led advance and future care planning service in Pembrokeshire and some of the challenges this service faces. They emphasised the importance of having in person conversations alongside completing ACP forms and the key role trained nurses play in delivering this.

SLIDES BELOW

Paul Sartori Foundation
Presentation to CPG Spotlight
on Advance and Future Care
Planning

Laura Hugman-Clinical Team Manager
Fay Morley-Advance and Future Care Planning Co-ordinator

paulsartori
HOSPICE AT HOME

1

Paul Sartori Foundation
Pembrokeshire Hospice at Home

- Trusted
- 40 years experience
- 17,000 hours of Nursing day and night respite care.
- 346 people died while in receipt of Paul Sartori Nursing and Respite Care, at home. 20% of all deaths registered in the county.
- 82% died in their preferred place of care
- Services are offered 365 days a year and easily accessible with a 24/7 on call Clinical line, issued to all the families known to us and colleagues in Health and Social Care

paulsartori
HOSPICE AT HOME

2

Paul Sartori Clinical Service

- Hospice at Home
- Equipment Loan
- Anticipatory and Bereavement Counselling
- Complementary Therapy
- Physiotherapy
- Education and Training
- Advance and Future Care Planning



3

Advance and Future Care Planning 1st April 2022 to 31st March 2023

- 3 Registered Nurses 1.2 WTE
- Service had been running for 8 years
- 164 referrals including from Consultants, Palliative CNS', Admiral Nurses, Marie Curie Dementia Nurse, GP, Patients, Family members and self-referrals.
- 161 discharges with 110 documents completed, 57% of referrals resulting in completed documentation of an ACP.
- Well adults (20%) = early intervention = cost savings
- 190 planners received 377 hours of support, averaging 2 hours each.
- 20% (68 of the 346) people who died in receipt of hands-on nursing and respite care in their own homes were known to the FCP team



4

Service Costs and Funding Sources

- Cost per annum £52,000
- Funding has been variable and complex, supported by Pembrokeshire GP clusters who have contributed each year
- Funding has also been partly covered by SLA with HDUHB linked to specific outcomes around referrals and training
- April 2021 Paul Sartori Foundation committed to the service, funding the co-ordinator role permanently from charitable funds
- Paul Sartori will always offer FCP to our service users and patients



5

Service Recognition and Awareness Raising

- Quality statement
- Established service 8 years
- During Covid PSF ACP team engaged with all Nursing & Residential Homes in Pembrokeshire, offering support, guidance and advice.
- National recognition.
- Gregynog's National Palliative Care Conference.
- Dying Matters week. 2 theatre productions, sell out audience, brilliant reviews.
- Numerous presentations and training sessions, official over 400, unofficial over 1000



6

Patient Story - May 2023

- The difference Paul Sartori Foundations FCP Service made to 1 family
- *"I honestly don't know how we would have managed if it hadn't have been for the Paul Sartori team. My Aunty's decline was so very quick – nothing was too much trouble. The team cared primarily for my Aunty but also for the wider family. She wanted to die at home with her family around and that was exactly what happened. The end of her life came in the way that she wanted – we felt honoured to be able to give that to her with the Paul Sartori teams help. I cannot find fault at all ! Thank you again"*



7

Local GP Practice Audit Results

- Clear evidence in patient records that presence of an ACP document prevented admission and ambulance call out in a number of patients.
- £10,000 per year for every practice based on admission avoidance, ambulance call outs alone.
- 13 practices in Pembs = potentially saving £130,000 per year.
- Future Care planning service costs £52,000 per year
- Highlighted the need to improve recording of data within one practice.



8

What Next for Paul Sartori Foundation's Future Care Planning Service?

- The local audit resulted in planning a more comprehensive recording of outcome measures. To be evaluated this year.
- Secure funding beyond March 2024
- With funding in place: sustain and develop the service/ succession planning /undertake further audit and Research opportunities
- Without funding: a significant service impact resulting in no provision of face-to-face contact; inability to sustain training; limited professional support to other colleagues, for example. Increase risk in inappropriate admission/ treatments

paulsartori
HOSPICE AT HOME

9

Thank you for listening

Any questions?

paulsartori
HOSPICE AT HOME

10

Mark Isherwood thanked Prof. Mark Taubert for agreeing to present on progress developing national Advance and Future Care resources at the next meeting of the CPG and apologised for the meeting running over time.

Jenny-Anne Bishop OBE from the Unique Transgender Network described some of the challenges trans and gender diverse people face ensuring medical records and other documentation are inclusive of trans and gender diverse identities, including Advance Care Plans and letters of last wishes. She asked Laura and Fay for their experience of including trans and gender diverse people in ACP?

Fay said their system only allows them to log people as male or female but they always respect and treat people how they individually want to be treated.

Mary Mitchell described her experience of ACP and highlighted the key role it can make for people with dementia.

AOB

Dates for future meetings will be circulated when confirmed by Mark's office.