

## Grwp Trawsbleidiol ar Hosbisau a Gofal Lliniarol Rhithiol

### Virtual Cross Party Group on Hospices and Palliative Care

11:30-12:30 25 Mehefin 2020,

11:30-12:30 25 June 2020

Cofnodion | Minutes

#### Yn bresennol | In attendance

• Mark Isherwood (Chair) AM	• John Griffiths AM
• Dai Lloyd AM	• Rhun ap Iorwerth AM

• Liz Andrews, City Hospice	• Deborah Ho, Ty Hafan
• Grant Usmar, Hospice of the Valleys	• Tracy Jones, Ty Hafan
• Andy Goldsmith, Ty Gobaith/Hope House	• Steve Parry, Nightingale House Hospice
• Luke Conlon, Compassionate Communities Pembrokeshire	• Thomas Davies, Macmillan Cymru
• Trystan Pritchard, St David's Hospice	• Catrin Edwards, Hospice UK (Secretary)
• Iain Mitchell, St Kentigern Hospice	• Emma Saysell, St David's Hospice Care
• Ann Williams, Bracken Trust	• Rhys Jackson, Older People's Commissioner's office
• Heather Ferguson, Age Cymru	• Jake Smith, Marie Curie Cymru
• Jonathan Ellis, Hospice UK	• Steve Parry, Nightingale House Hospice
• Andrew Wilson-Mouasher, Marie Curie	• Melanie Minty, Care Forum Wales
• Dominic Carter, Hospice UK	• Rini Jones, Hospice UK
• Elin Llyr, Deryn	• Jonathan Pearce, Hospice of the Valleys
• Laura Hugman, Paul Sartori Hospice at Home	• Sue Williams, Macmillan Cymru

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## Croeso | Welcome

- The Chair, Mark Isherwood (MI) welcomed all to the inaugural virtual CPG Hospices and Palliative Care, serving as an update from the sector during the Covid-19 pandemic and recovery. This sees a pause to the CPG's deep dive work on Compassionate Cymru.

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MI noted that we were gathering together during Children's Hospice Week, and thanked colleagues working in that field.

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Minutes from the previous meeting, 11 March 2020, were confirmed by Grant Usmar (GU) and seconded by Andy Goldsmith (AG).

MI referred to the meeting papers, which included a letter from the Chair to the Minister for Finance and Trefnydd, which advocated on behalf of appropriate funding for the hospice sector during Covid-19. MI ask Catrin Edwards (CE) to confirm that there had been no reply to that letter as yet.

## Cyflwyniad | Presentation: Andy Goldsmith, Tŷ Gobaith

### **Paediatric Palliative Care during the Covid Crisis and into the 'New Normal'**

- Please see Power Point slides in appendix.
  - Tŷ Gobaith and Tŷ Hafan have responded jointly to the Covid-19 pandemic
  - During the height of the pandemic, Tŷ Gobaith continued to provide end of life care for children in their own homes and were providing end of life care at the hospice at the time of the meeting.
  - Family centred care has had to be reimagined because of social distancing regulations and the significant number of families shielding
  - A 'virtual hospice' offering has been made available and working well. This includes virtual symptom control.
  - Whilst virtual services are working well, planned respite and short break care must remain a core offering for families once hospices can ensure they are safe spaces during the country's response to Covid-19.
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- Deborah Ho (DH) noted the significant collaboration and cooperation across operational boundaries during the crisis. 100 days into the crisis, adaptations to services are now being stress tested as families could reach crisis points. For this reason, the virtual offering must work alongside the face to face short breaks when safe to do so.
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## Cyflwyniad | Presentation: Laura Hugman, Paul Sartori Hospice at Home

- Partnership working to achieve rapid discharge home at end of life

- Increased case load during Covid-19: 16 March-12 April 2020, 12 people (non-Covid) were supported to be discharged from hospital to home at end of life in comparison with only 4 people for the same period in 2019.
- Rapid discharge from hospital to home facilitated by a Hospital Coordinator post, which was introduced in February.
- The increased case load in 2020 is indicative of unmet need in previous years and will steer expected case load going forward.
- Case study:
  - Family wanted their relative to be discharged home at the end of life, from a hospital that was out of the local area.
  - Paul Sartori coordinated the discharge with the family's wishes at the centre.
  - Equipment, including a hospital bed, was despatched to the home on the same day.
  - Day and night respite provided by Paul Sartori.
  - Additional care was provided through coordinating with the integrated hub, including liaison with district nurses.
  - Out of hours service did not need to attend.
- Advance Care Planning service has continued. Proactively contacted care homes to support with ACP. Of 1,000 care home residents in Pembrokeshire, a third now have ACPs.
- The training lead has been working with Junior Doctors during the pandemic to practise and develop their skills breaking bad news.
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## Cyflwyniad | Presentation: Emma Saysell, St David's Hospice Care

- Service adaptations and lessons learnt
- St David's Hospice Care serves a population of 600k. In April 2020, there were 1,250 people on the caseload, including 200 new referrals.
- Implemented a virtual assessment model but 700 face to face assessments were made at the height of the pandemic.
- All clinical teams were moved out of the office to reduce transmission.
- There were 183 deaths during April, of which 160 received their Preferred Place of Care and Preferred Place of Death. Of these, 30 were Covid-19 positive.
- May saw a 25 per cent increase in demand for Hospice at Home.
- Challenges:
  - Some staff were redeployed into ABUHB because of experience in ITU.
  - Night staff wearing PPE for 9 hours straight.
  - ABUHB have been good at ensuring PPE reached hospice staff.
  - Contingency plans to ensure a new model of delivering EOL medication should there be insufficient syringe drivers during a peak were only used once, but worked well.
- Lessons:
  - We can work differently and virtually but people's preference continues to be face to face

- Clinical meetings can take place virtually
- The hospice service is integral to the NHS system and we can work well together
- Staff have been excellent – have worked hard in people's homes and care homes.

## Cyflwyniad | Presentation: Jonathan Pearce, Hospice of the Valleys

Bereavement care: meeting current and future need

- Hospice of the Valleys use a model based on resilience, which include pre-bereavement care where this is possible. Whilst some people will need professional support, most people will manage with informal support.
- During Covid-19 they have offered phone support and virtual bereavement counselling, but there has not been a huge take up of the latter. This highlights the need for face to face support as we move forward.
- Covid will have an effect on the social, emotional and economic wellbeing. The psycho-social context of deaths has an impact on the bereaved. During Covid our social connections are curtailed, which exacerbates grief.
- Socio-economic context affects grief, which is particularly relevant in the population of Blaenau Gwent. The social work team at Hospice of the Valleys is working well with the Department for Work and Pensions.

## Cyflwyniad | Presentation: Trystan Pritchard, Hospices Cymru & St David's Hospice

Hospice funding – Covid-19

Consistent messaging from Welsh Government throughout the pandemic that hospices are core, vital and essential. This is the service and relationship hospices want with the NHS.

Difficult economic planning environment: Only 16% of income is statutory funding. Covid meant the potential loss of 90% of fundraised income. As charitable organisations hospices can use some of their reserves but have a responsibility to hold a proportion to guarantee our sustainability.

- Of the £6.3m support announced by Welsh Government, only £2.1m has been released. As part of this financial support, hospices have accepted unprecedented levels of monitoring.
- Asking Welsh Government for an update on the timescale of the funding and assurance that the £6.3m will be distributed. A settlement should allow for the seasonality of income generation and should not punish those hospices that have fundraised innovatively.
- A conversation on the longer term funding of the hospice sector must also be taken forward.
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## Cyfleoedd a phwyntiau gweithredu | Opportunities and actions

MI noted that the notional Barnett consequential funding coming to the Welsh Government from the UK Government's commitment to support hospices in England

up to £200m in Quarter 1 of 2020 was £12m. The £6.3m earmarked for hospices in Wales falls significantly short of this figure.

- **Hospice UK and Hospices Cymru are jointly writing to the Minister to advocate for the funding announced to support hospices to be released.**

Catrin Edwards (CE) noted that the Welsh Government's anticipated Bereavement Framework will need to be updated in light of the anticipated increase in demand for bereavement care following Covid-19 and this could be a fruitful avenue for the CPG to pursue in light of Compassionate Cymru work.

- **CE to liaise with the secretariat of CPG Funerals and Bereavement regarding joint work.**
- **CE and MI to work together to put forward written questions to the Minister for Health and Social Services.**

Melanie Minty (MM) extended thanks from the care home sector to those hospices who have supported them during the crisis. MM noted hospices' role in supporting the role out of ACP in care homes in particular.

Dominic Carter (DC) asked colleagues what support staff have needed to take their work virtual.

Laura Hugman (LH) noted that the team at Paul Sartori have been resilient but some have needed support from counsellors. Bereavement counsellors have raised the additional effort needed in consultations without the visual and physical cues of a face to face consultation. This has led to the need for additional clinical supervision. CE asked whether there is any intention for the Welsh Government (or other body) to evaluate the impact on virtual consultations, whether that be for palliative care or more widely across the health and care system.

Dai Lloyd MS (DL) noted that evidence received by the Health, Social Care and Sport Committee Inquiry into the response to Covid-19 indicated that virtual consultations are generally thought to be going well, though face to face services are still needed and valued. DL noted that evidence to the Inquiry was received from the hospice sector.

- **CPG should await the Health, Social Care and Sport Committee's series of reports on the response to Covid-19 and take forward any relevant areas of work.**

MI considered what role the CPG could play in ensuring appropriate, sustainable funding is secured for hospices during this year.

CE noted that a letter from Hospice UK and Hospices Cymru was to be sent to the Minister imminently.

Trystan Pritchard (TP) noted that discussion should remain within formal channels between hospices and the Welsh Government for now. The support of the CPG will be called on should there be further delays.

- **CE and TP to keep the CPG informed of developments.**

- Any hospice wishing to share concerns should feel welcome to contact MI.

Luke Conlon (LC) highlighted the role Compassionate Communities Pembrokeshire have seen virtual connections play in bringing men's groups together in safe talking spaces. This is learning to take forward in future projects.

## UFA | AOB

- Date of the next meeting: 23 September – details to be confirmed

## Appendix

### Cyflwyniad | Presentation: Andy Goldsmith, Tŷ Gobaith

**Paediatric Palliative Care during the Covid Crisis and into the 'New Normal'**



**Paediatric Palliative Care during the Covid Crisis and into the 'New Normal'**

Presentation to the CPG on Palliative and End of Life Care

Early March	April Ongoing in June	June	July onwards	Early 2021
Resolve	Resilience	Return	Reimagination	Reform
Address the immediate challenges that COVID-19 represents to whole workforce, patients, carers, donors, technology and NHS and Social Care partners	Address cash flow management challenges and resilience issues during virus-related shut down of shops and fundraising events.	Create detailed plans to return business to scale in the new "Business as Unusual" as COVID-19 situation evolves and knock-on effects become clearer	Reimagine the next normal: what care and income generation looks like and implications for how as a charity we should reinvent ourselves	Be clear about how regulatory and competitive environments may shift  The needs of children and family may change  New fundraising activity

From McKinsey and Company:  
Beyond coronavirus: The path to  
the next normal



## Delivering a resilient service during Covid

- The basic principles of relieving pain and symptoms and caring for the psychosocial needs of children and families through touch and physical presence are often no longer possible during the pandemic.
- Many families advised to shield and families were not keen to leave the safety of their own homes, preferring to cope with existing care packages or on their own.
- Some families continue to decline the offer of hospice support for fear that the hospice staff might inadvertently bring COVID-19 into their homes.
- Challenge of delivering compassionate care including care at death whilst wearing PPE
- Constraints created by social distancing on the normally unrestricted child and family centred care at the hospices.







Service	Converted/New	Focus
Kindness calls - clinical check-in	New focus	Child and family
Bereavement support and counselling	Converted	Bereaved family
Virtual symptom control appointments	Converted	Child
Storytelling	New	Child and sibling
Letter writing	New	Sibling
Virtual Physio	Converted	Child and family
Virtually delivered activities (e.g., crafts, exercise)	Converted	Child and sibling
Government support maximisation	Converted	Family
Remembrance days	Converted	Family

## Reimagining the service

- Safe respite in the hospices (both planned and emergency) remains a priority for families:
  - Capacity of hospices whilst maintaining social distancing
  - Enabling interaction between staff and children
  - Family care and stays at the hospices
- Delivering compassionate Covid secure end of life care at place of choice
- Building on the virtual hospice services to deliver efficient, accessible and effective care



## Cyflwyniad | Presentation: Trystan Pritchard, Hospices Cymru & St David's Hospice

Hospice funding – Covid-19





## **Hospice Funding – Covid 19**

**Trystan Pritchard**  
**Chairman, Hospices Cymru**

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- Consistent WG statements that Hospices are 'core' 'vital' and 'essential' to End of Life Care in Wales
- Strong partnership approach with NHS, Social Services and other providers
- Providing services at end of life that are simply not available elsewhere

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- Hospices receive as little as 16% statutory funding for services
- Hospices typically deliver £5 of services for every £1 public funds
- Over 22,000 patients and families benefited Wales over last 12 months



#### **Covid-19 Effect**

- Loss of up to 90% of income generation
- Shops closures cancelling fundraising events, decrease in donations, impact on reserves an investments
- Sector is fragile due to uncertainty and need to use core reserves
- Some hospice face a cliff edge before the end of 2020



#### **Covid-19 Effect**

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#### Welsh Government Support

- £6.3m pledged in April and gratefully acknowledged
- £2.1m distributed in month 1
- No further distribution so far
- Reporting requirements agreed and required scrutiny accepted
- Strict scrutiny at a time when Hospices are dealing with Covid-19 situation hampering ability to plan and deliver services beyond short term
- Delays causing instability and forecasting requirements on future income arbitrary
- Timescale and assurance needed on distribution of remainder of £6.3m



#### Current normal time funding

- As low as 16% for some inpatient services and around 25% overall
- Welsh hospices generally receive 50% of statutory funding as compared to England and Scotland
- WG has previously stated that Hospices benefit from other NHS contributions but this has dwindled as pressures on services intensified
- No inflationary uplifts for over 10 years
- Equates to £89 per night in some hospices where care homes receive basic £112
- Hospices are a specialist, Consultant-led service
- WG figure for a specialist palliative care bed is £721 per night
- Hospice often admit directly from ITU and acute beds



Told we are part of the NHS family, but feels like a poor relation

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#### The ask from Hospices Cymru

- Commitment to distributing the full £6.3m to hospices with a clear timescale
- Make allowances for highly seasonal nature of hospice fundraising and avoid punishing hospices for innovation during the crisis.
- Commit to a realistic and accelerated timescale on reviewing statutory hospice funding to safeguard the sector and protect local specialist services that are not available elsewhere