

## Grwp Trawsbleidiol ar Hosbisau a Gofal Lliniarol Cross Party Group on Hospices and Palliative Care

19 Chwefror 2019, Ystafell Gynadledda 5, Ty Hywel

19 February 2019, Conference Room 5, Ty Hywel

Cofnodion | Minutes

### Yn bresennol | In attendance

Mark Isherwood (Chair) AM	Dr Dai Lloyd AM
Liz Andrews, City Hospice	Kay Jeynes, CVUHB
Stephen Bassett, NHS 111/ABMUHB	Ian Jones, Glyn Ebwy surgery
Kathleen Caper, Hospice UK	Tracy Jones, Ty Hafan
Paula Davies, CVUHB	Sarah Lloyd-Davies, Marie Curie
Catrin Edwards, Hospice UK (Secretariat)	Greg Pycroft, Macmillan
Stephen Edwards, ABUHB	Monica Reardon, Marie Curie
Carolyn Gent, Marie Curie	Ruth Richardson, PtHB
Andy Goldsmith, Ty Gobaith/Hope House	Emma Saysell, St David's Hospice Care
Paul Harding, Marie Curie	Kevin Thomas, MNDA
Laura Hugman, Paul Sartori Hospice	Andrew Wilson-Mouasher, Marie Curie

### Ymddiheuriadau | Apologies

Helen Mary Jones AM	Llyr Gruffydd AM
Mohammad Ashgar AM	Gary Doherty, BCUHB
Steve Parry, Nightingale House Hospice	Iain Mitchell, St Kentigern Hospice
Debbie Jenkins, ABUHB	Richard Bowen, NHS 111
Jina Hawkes, HDUHB	

### Cofnodion y cyfarfod diwethaf | Minutes from the last meeting

Minutes confirmed.

Matters arising:

CPG gave evidence to the Health, Social Care and Sport Committee on 13 December. The Committee has recently launched an [inquiry into District and Community Nursing](#), which will include its role in the provision of palliative care.

## Gofal Iliniarol allan o oriau | Palliative care Out of Hours (OOH)

Attendees were directed to the CPG's letter dated 10 October 2018 to all health boards and NHS 111 regarding the 2018 Inquiry recommendation on the consideration and resourcing of adult and paediatric palliative care out of hours. It was noted that all health boards and NHS 11 had responded to acknowledge receipt of the letter and to confirm their willingness to engage with the CPG, including by attending this meeting.

Presentation from Dr Stephen Bassett, NHS 111 and ABMUHB

- NHS 111 is the 24/7 free phone service which serves as the single point of access to OOH primary care.
- Currently rolled out in ABMUHB, HDdUHB and PtHB. Will be operation in ABUHB from April 2019, CTUHB from Autumn 2019 and BCUHB and CVUHB in 2020.
- Recent reports, e.g. [Marie Curie and RCGP](#) and evaluation of Shropdoc OOH service have been critical of OOH palliative care provision but indicate that the barriers are logistical only and improvement should be possible.
- 4 areas where NHS 111 have identified challenges and opportunities regarding OOH palliative care:
  1. Single point of access and coordination
    - The system links up automatically with all GP practices and special patient notes, such as those held on palliative patients, are flagged up to call handlers.
    - This prevents the automatic response of calling an ambulance for emergency admission. A decision to admit the person would need to be made by a clinician.
    - Can coordinate District Nursing provision directly.
    - Allows for the regionalisation of senior clinical advice. Currently recruiting a palliative care advisory for ABMUHB and HDUHB areas.
  2. Advance Care Planning
    - A better facility for contributing to ACP was needed.
    - If a patient is recognised as palliative but does not have an ACP in place the clinician can note whether an ACP would be useful. This triggers a report to the GP.
  3. Electronic communication, including prescribing

Have established links with the District Nursing system in ABMUHB and HDUHB.

#### 4. Logistical (equipment, medication and stock)

Geographic: health board administrative boundaries and GP practice location may not always coincide for each patient.

Administrative: staff can feel anxious administering controlled drugs.

People: not everyone is clear about their role in the process, or some people can be restrictive about their contributions, seeing it as the work of others.

- Progress has been made with the OOH service moving from being primarily GP-based to seeing it as a service that provides multi-discipline urgent care.

Presentation from Andy Goldsmith, Ty Gobaith

## End of life care at home for children in North Wales

A new approach

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## The problem we are trying to solve?

- Estimated around 20 children (age 0-18) die each year in North Wales from a terminal condition. 80% die in hospital, only 10% at home.
- Evidence suggests that when a choice is available parents and children would like to die at home, as long as it is safe and symptoms are controlled
- Getting a child home one last time is important for parents
- Dying at home is often not possible due to lack of medical, nursing and pharmacy support- Currently provided by goodwill

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## A new model of care

- Integrated EOL nursing team
  - Diana (children's community) nurses, Tŷ Gobaith Children's Hospice nurses, Cystic Fibrosis nursing team, Oncology nursing team, Technology Dependent nurse
- Common pathway for EOL care across all partner services
- Co-ordination provided by Tŷ Gobaith
- Shared portfolio of specialist equipment
- Out of hours consultant cover
- Out of hours pharmacy cover via hospital pharmacy



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## Team around the child

- All nurses part of 'one' virtual team
  - Practicing privileges in hospital and hospice
  - Working one hour from home
  - 2 Nurses on call at night
- Nursing care and specialist consultant support
  - Symptom control
  - 24/7 consultant telephone support
  - Administration of medication



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## What was the catalyst?

- Changes in personnel
- Successful bid from Tŷ Gobaith to Betsi Cadwaladr UHB for 2 years of nurse part funding (funded from non recurring EOL Board funds)
- Funding from the EOL Board for additional paediatric palliative care consultant sessions in North Wales
- Willingness and commitment of all parties to make this work



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## Case study

- December 2018
- Child few weeks old never left hospital- Incurable degenerative condition
- Parents wanted to take her home and if possible for end of life to be at home
- Arrangements put in place to transfer from
  - Glan Clwyd hospital to Tŷ Gobaith for step down care
  - Ty Gobaith to home for a few days
  - Home to Tŷ Gobaith when parents got scared
  - End of life on Christmas Day at Tŷ Gobaith.



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## Next Steps

- Go live from 1<sup>st</sup> March
  - Commit to make it happen, let paperwork catch up
  - Practice, learn, adapt.
- Test medical cover- GP support
- Formal launch in June
- Extend model to neonates (from 24 weeks gestation)
- Extend model for young adults up to age 25
- Specialist consultant cover based in North Wales
- Prove model works and secure sustainable funding



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Discussion on both presentations:

### Pharmacy

Dai Lloyd: Just in Case medications should be in place by now, though it is clear that this isn't always the case. Families also need to have had the appropriate level of conversation about ACP for JIC medications to be utilised.

Andy Goldsmith: Children often cannot be discharged from hospital on a Friday evening until Monday, when pharmacy is operational. Pharmacy should be available 24/7.

Tracy Jones: JIC not working as well for paediatrics as many medications can be off licence or rate. A new part time pharmacist is now employed by Ty Hafan but this will only go some way to addressing gaps OOH.

Mark Isherwood: Considering a greater role for community pharmacists to facilitate better OOH access to medication.

Kay Jeynes: Health boards are investing in Community Pharmacists for OOH. Big pharmacy companies no longer see OOH as commercially viable.

Stephen Bassett: Children should be discharged from hospital with hospital medications. Each staff member needs to be flexible in their approach and to take responsibility rather than seeing things as others' responsibility.

JIC is not used well universally, or the box is present but fails to be administered.

We could look towards remote medications management in future.

Emma Saysell: Community pharmacy system is working well in ABUHB with medications transported by taxi from pharmacy to patient home.

Stephen Bassett: need a flexible approach to prescribing OOH with the most appropriate clinician during the period issuing the prescription.

Electronic prescribing across Wales is far off being a reality. In that respect, Wales is behind England.

### Paediatrics

Tracy Jones: Query as to whether NHS 111 is connected with Paediatric Community Nursing Teams, as with District Nurses.

Kay Jeynes: The GP remains central even for paediatrics, for both the child and their family.

Ruth Richardson: GPs will not always be in contact with children who have very complex needs.

Children at End of Life are eligible for Continuing Care but nursing resource is limited, especially in rural areas such as Powys. Reliant on the goodwill of nurses who travel long distances. This model is not sustainable over longer periods.

Andy Goldsmith: Hoping to roll out the EOLC model across the hospice areas in England and Wales. Will work with Ty Hafan to try to overcome the challenges of rurality in Powys.

### 24/7 specialist advice line

Mark Isherwood: the CPG's Inquiry referred to the resourcing of the 24/7 specialist advice line.

Emma Saysell and Andrew Wilson-Mouasher confirmed that that St David's Hospice Care and Marie Curie operate the line in their respective areas.

### **Pwyntiau gweithredu | Action points**

- Chair to write to the Health Minister to seek clarity on the Welsh Government's intentions to ensure progress and coordination on palliative care in Wales following the dissolution of the End of Life Care Board in 2020.
- Questions to be submitted to the Minister on the provision of OOH pharmacy and medications.

### **UFA | AOB**

- Marie Curie lecture – 19 February 2019, 18:30, Pierhead
- Marie Curie Daffodial Appeal launch – 20 February 2019, 12:30, Senedd
- Dr Ian Jones, GP at Glyn Ebwy surgery, has recently completed research into the hospital admission of care home residents at the end of life. Please contact Ian directly for further information.