GTB Hosbisau a Gofal Lliniarol

CPG Hospices and Palliative Care

Roundtable 14 February 12-13:30, Ty Hywel

Present:

Mark Isherwood AM (Chair), Dai Lloyd AM, Rhun ap Iorwerth AM, Jane Hutt (AM)

Andy Goldsmith Angie Contestabile, Ann Brennan, Ann Williams, Ashley Melons, Beth Morgan, Carol Killa, Catrin Edwards (Secretariat), Des Brown, Elen Jones, Elizabeth Humphreys, Emma Saysell, Grant Usmar, Dr Ian Back, Baroness Ilora Finlay, Iwan Hughes, James Cooper, Jo Oliver, Joseph Carter, Julia David (Office of Jayne Bryant AM), Karen Wright, Kathleen Caper, Kevin Thomas, Laura Hugman, Lesley Bethell, Lisa Jones, Lisa Turnbull, Dr Mel Jefferson, Mel Lewis, Monica Reardon, Nic Smith, Pat Combs, Paul Harding, Rachel Lewis, Richard Pryce, Rob Jones, Dr Susan Thomas, Suzie Howe, Tony Curtis MBE, Vikki Reynolds, Wendy Hobbs.

Apologies:

Janet Finch-Saunders AM, Jayne Bryant AM, Julie Morgan AM, Llyr Huws Gruffydd AM, Simon Thomas AM

Carol Davies, Daisy Cole, Dinah Hickish, Fiona McDonald, Iain Mitchell, Janette Bourne, Mike Walsh, Morgan Griffiths-Davies, Pip Ford, Trystan Pritchard

Discussion notes

Paediatric Palliative Care

Theme	Challenge	Opportunity
Nature of life-limiting conditions in children and young people	Varied conditions High needs	
Workforce	Care packages reduced due to staff capacity, not changes in need	Joint posts between statutory and third sector Trained volunteers may not be able to provide direct care

	Agency workers: • Better care delivered when staff know the child • Not always trained to use equipment – can't care safely Allocating hospice staff to community means pulling staff from hospice Nursing bursaries cut Emotional strain	but can offer support with routine tasks and can be support to families when in hospital with children
Strategic planning of services	Lack of insight/data on number of children with needs, and clarity on 'eligible' need Cross-border provision Split between care in the home and residential provision	Better data would enable better planning for hospices Hospices and voluntary sector should be involved in the design of health board services Hospices should contribute to IMTP
Integrated services	Children's CHC framework 'not working' Separate input from health, education, and social care Transition – feared by parents Parental involvement limited, and no feedback on why decision made	Role of key worker Advocacy for parents

Meeting needs – widening access

Theme	Challenge	Opportunity
Conditions that could benefit from palliative care		Hospices and PCT on MDT from the outset PC should be delivered in parallel with specialist teams to ensure timely/early referral Education pre-registration for healthcare staff about PC e.g. students follow set of patients over 6 months to see their 'whole' journey
Underrepresented groups	Language – phone translation or family interpretation is inadequate	Workforce training in Welsh so care can be delivered in Welsh
Understanding localities – culture and data	Needs assessment (informed by Higginson – i.e 0.75% of pop. with adjustment for death rate and morbibdity) not always used for service and workforce planning, incl. skills needs and gaps	Need to have contact with community leaders Must understand where people seek advice/guidance in their communities A more robust needs assessment process would use the

		Higginson data + locality knowledge
Integration with Social Services	Social Services resources protected – hospice referrals are seen as CHC only Barriers to getting the right people around the table Legislation on integration not yet led to cultural change	Reaching out to involve Social Services Referrals should be taken from SS
Workforce	Mixture of pump priming, seed funding and charitable funding leads to inconsistent staffing Adult and Paed community nurses working in silos	Widening skillset and experiences of staff – not silo working
Systems and structures	National reporting and outcomes focus on efficiency, not effectiveness (for people) Systems can be culturally insensitive e.g. lack of registrar to release body on weekends impacts on people of specific faiths who require expedited burial Hospice referral speed – formal and time consuming Hospice practice to hold bed for 24hrs after a death is outdated	Move towards valuing effectiveness over efficiency - a quality approach Feedback loops needed across systems Referrals should be taken from social care settings – demedicalise palliative care

A good death in any setting

Theme	Challenge	Opportunity
Expectations	Some families expect 24hr care in the community – this isn't achievable – others expect 2 visits a day	People want the right care, delivered by the right person, at the right time – labels such as PC or EOLC, or service boundaries aren't relevant Better information sharing about what PC is and what's possible
Location of death	Preferred Place of Death and/or Care taken as the primary measure of a 'good death' – but this simplifies what is a complicated issue, and can and does change Home death difficult for people living alone, people in rural areas	Macmillan supporting paramedics to reduce emergency hospital admission at EOL

	Access to hospice depends on availability at that time People are frightened – admission to hospital (but not always a bad thing)	
Integration	Divide between Health and Social Care	Multi-agency approach needed Training of care home staff
Advance Care Planning		Electronic ACP accessible to all services Needs to be more readily discussed by professionals with people

Building capacity and resilience to care in the community

Theme	Challenge	Opportunity
Carers	Carer may also have health needs Can be overwhelmed with too much information Long waiting lists for carers assessments	Families need upskilling to support person to die at home – C&VUHB developing training CARIAD project (Dr Anthony Byrne) to pilot supporting carers to administer injections
Usual residence	People living alone – often unrecognised/identified. Less likely to achieve care preferences. Older people living alone – decisions to let them return home alone and capacity to choose Learning Disabilities – when seen by PC, usual home/supported living seen as unsuitable – transferred to new home at EOL Care homes: not always aware they can have night sitters. Staff don't always have expertise to care at EOL Dementia care units/homes often not taking palliative approach/offering EOLC	Upskilling nursing home staff C&VUHB offer a free degree on EOLC for care homes (not all places taken up) Commissioning between HB and care homes should consider skills mix, including prescribers HB to provide Bank backfill for staff on training?
Primary Care	GP as default DN workload	MDT approach Greater role for pharmacists – access to PCRegister, support for families, JIC boxes – better guidance needed, stocking drugs – capacity and rurality More independent prescribers – leads to better continuity of care as no need for locums

Out Of Hours	No OOHGPs in some HB areas – not an appealing job (money not the issue) CTUHB and C&VUHB 24/7 DN service	'The Gold Line' – Airedale NHS Foundation: 2 CNSs on call, can respond to OOH calls, OOHGP contacted only when beyond their capability. Using telemedicine and videocall. 1/3 of calls resolved without further referral. https://ico.org.uk/media/1624219/preparing-for-the-gdpr-12-steps.pdf Telemedicine for Wales – rural and urban? Incentivising GPs through contracts MDT approach to OOH Greater role for pharmacists – note only Just In Case Boxes Paul Sartori Hospice takes on role of coordinating OOH in Pembs – reducing DN load
Integration	Delayed Transfers of Care due to lack of social care Rapid discharge not always working	Directory of services, e.g. DEWIS, but needs better promotion