

Health and Social Services Committee

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Date: Wednesday 15 November 2006

Venue: Committee Room 1, Senedd, National Assembly for Wales

Title: Response from Claire House Children's Hospice, Bebington, Wirral, to the Committee's Consultation on Cancer Services for the People of Wales

1	How can information technology be used more effectively to track and facilitate the patient's journey?
Response	The NW Cancer Network Group is setting up a data base to track patients and to share information with a view to informing the group working on the Care for the dying Pathway. Also to develop a 'Passport ' with all relevant information for the patient to hold.
2)	How effectively is research and good practice being integrated with service delivery? What can be done and by whom to improve this?
Response	Alderhey and the Children's Palliative Care Team share information on Palliative Care for Children, and Care of the Dying Pathway with the NW Palliative Care Forum. This seems a good model. Lind Brooks at Alderhey, a Consultant in Palliative Care has more information.
3	What are your views on the complexity of commissioning services? Is the process hampered by the involvement of the local health boards, cancer networks and Health Commission Wales? How could it be simplified?
Response	In England the complex needs of these children allows some services eg .Social Services to avoid their responsibility to provide services and support eg Respite services by over medicalising the child. Thus children can end up having respite in Hospital and blocking a bed, or taking up beds in ITU. This is where Hospices for Children come in, we provide a very different service to Adult Hospices. It could be simplified in my view by setting up Services for Children which cross all agencies, and meet all needs of children ie Health, Care Education ,Protection etc .to prevent the argument re whether Health need, Social need and whose budget foots the bill.
4	What evidence is there of the value of screening and immunisation?

Response	No reponse
5	What are the barriers to the NHS in Wales keeping abreast of, and responding to, developing technologies and therapies? How might these barriers be overcome?
Response	No reponse
6	How can the NHS and the voluntary sector work together more effectively to deliver services?
Response	In England the models developed by the NW Palliative Care group, working with Children's Hospices, prevents beds in Hospitals and especially ITU being taken up by these children with very complex Health needs who need Care not necessarily Treatment. We can provide Care from Qualified and Competent people in a Home from Home environment, at less cost than a Hospital or ITU bed.
7	How can the collection and use of data on where the terminally ill spend their last weeks or months be improved better to inform service provision for those people?
Response	Data base being developed by Linda Brooks is a good model, leading to Care of the Dying Pathways agreed with each individual patient allowing the necessary resources to be planned for and used more effectively eg. planned admission to a Hospice rather than Emergency admission through A and E. Individual Agreements re Ventilation and Resuscitation shared with all partners.
8	There are a number of issues around prescribing and the cost of drugs:
8(i)	What should be done and by whom to reduce continued prescribing of inappropriate drugs?
Response	Who decides what drugs are inappropriate? Many of these children have such complex needs that their treatment is very individual and innovative care and drug regimes are needed to keep them comfortable. The Consultant should be empowered to prescribe whatever they think is appropriate, on saying that we are lucky in the NW to have access to the Palliative Care Team who have a wealth of knowledge and experience ,and a lot of the services are Nurse led, once the Pathway has been agreed.
8(ii)	Should people who are prepared to pay privately for drugs not available to them on the NHS, be able to do so without having to become private patients and having to pay for all their treatment?
Response	If the drugs are deemed appropriate by the partners in Care they should be available on the NHS. Any other way leads to a 2 tier system for 'have' and 'have nots', particularly unfair when applied to dying children

8(iii)	Do doctors, pharmacists and other health professionals have adequate access to independent advice and guidance on the prescribing of drugs?
Response	They are best to answer this Q. We have 4 GP's who provide a 24/7 GP service to the Hospice and liaise with the child's Consultant and the Palliative Care Team. We also run training courses that they can access and meet regularly to discuss issues.
9	Are services centred on the patient, with service users consulted? If not what are the reasons for this and how can patient involvement be improved?
Response	At CH we run Child Centred Services, parents often come to us feeling disempowered. We employ a SW and a Family support worker and hold regular Parents meetings and meetings of siblings. We also send out Q's. Difficult area with 16-25 (and older)patients with transition as Adult Services are often not able to provide appropriate services for these young people and they end up with nothing or dying in inappropriate places and less than ideal circumstances , negating previous good work.