



Difficult Decisions in Paediatrics

Difficult Decisions in Paediatrics: Joined-up Working in Wessex

Friday 2nd November 2018 0830-1630

DoubleTree Hilton, Chilworth, Southampton SO16 3RB

A two-part Channel 4 documentary about paediatric end of life decisions in the Wessex region, broadcast earlier this year, highlighted how complex and difficult these discussions can be. We realised there was an appetite for a forum through which joined-up working in Wessex could be facilitated, where multidisciplinary discussions could be held and where the difficult ethical issues raised could begin to be discussed. This day aims to explore some of the most challenging discussions that need to be had in paediatrics and discuss if and how a regional paediatric Clinical Ethics Committee might help future cases.

Aims of the day:

- Examine challenging paediatric cases and difficult decisions from a range of perspectives
- Sharing stories and connecting clinicians across DGH, tertiary care and community to start the conversation around difficult decisions; how do we make ethical, family-based, resource-considered decisions based on the best interest of the child in a healthcare environment that sometime offers treatment because it is available
- Explore the opportunities for joined-up working between community, specialist and general paediatricians to ensure cohesive and consistent decision making for children with life limiting conditions and those who are reaching the end of their lives
- Highlight the role of the Clinical Ethics Committee (CEC) and discuss the place of a regional paediatric CEC

The 'Tragedy' of Charlie Gard

Our plenary speaker is Jonathan Montgomery, Professor of Healthcare Law at University College London, formally University of Southampton. Jonathan is previous Chair of the Nuffield Council on Bioethics and Chair of the Health Research Authority

Programme

Chaired by Anneke Lucassen, Professor of Clinical Genetics, and hon consultant. Chair UHS Clinical Ethics Committee

8.30	Registration, coffee	
9.00	Welcome and introduction	Peta Coulson-Smith
9.15	Case presentation: working together for the patient	Rowena Staples
9.40	Role of the UHS Clinical Ethics Committee	Angela Fenwick
10.00	Conflict and Communication	Robert Wheeler
10.30	Coffee	
11.00	Conflict, Moral Distress and Difficult Decisions: Can We Look After Everyone?	Peter Wilson
11.20	<u>Plenary</u> The 'Tragedy' of Charlie Gard	Jonathan Montgomery
12.15	Lunch	
1.15	Difficult Decisions: A Parent's Story	Stephanie Nimmo
2.00	The regional and national perspective – introduction to group discussion	Peter Wilson
2.15	Discussion: how do we make joined-up difficult decisions in Wessex?	
3.15	Coffee	
3.40	Feedback from group discussion. Is there an appetite for regional paediatric CEC and if so, what are the next steps?	Facilitators
4.20	Summary of the day	Peta Coulson-Smith
4.30	Close	