

Conference Outline Programme

Day 1: Chair: Professor Sir Alan Craft

| Time | Title of Session | Speaker |
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| 09.30-09.40 | Chair's Opening | Professor Sir Alan Craft, President, Together for Short Lives & Emeritus Professor of Child Health, University of Newcastle |
| 09.40-10.30 | Future-proofing our models of care | Dr Hilary Cass OBE, Chair, Together for Short Lives |
| | Mapping Chaos | Dan McAvoy, Parent |
| | The challenges we have seen and how we plan to address them | Andy Fletcher, CEO, Together for Short Lives |
| 10.30-11.00 | Panel Discussion on the challenges facing the sector | |
| 11.00-11.45 | Morning Break & viewing exhibition/posters | |
| 11.45-13:00 | 1. Workshop: Outcome measurement in paediatric palliative care; reflecting on the current state of play and assessing future | Lorna Fraser, Professor of Epidemiology & Director of the Martin House Research Centre and George Peat, Research Fellow, Martin House Research Centre |
| | 2. Abstracts: Understanding the population of babies, children and young people | 5. How many eligible children miss out on paediatric palliative care? An analysis of local death data and a survey of paediatric staff perceptions and barriers to referral. Dr Hannah Opstad, Barnet General Hospital / Noah's Ark Children's Hospice. 13. How do children with medical complexity die? A scoping review. Dr Grace Ng, Assoc Consultant, HCA Hospice Care, Singapore. Mapping of children's palliative care service provision James Cooper, Head of Policy, Together for Short Lives and |
| | 3. Abstracts: New service models | 28. Working across boundaries to enable choice: Outcome and process learning from a pan-ICS area extended hours community children's end of life nursing care pilot project. Dr Amy Volans, Consultant Clinical Psychologist, East London NHS Foundation Trust 19. The challenges and realities of remodelling children's hospice care. Katie White, Head of Children's Services, Havens Hospices. 38. Regional perspectives on the coordination and delivery of paediatric end of life care in the UK: a nested qualitative study. Dr Andrew Papworth, Research Fellow, Martin House Research Centre. |
| 13.00-14.00 Lunch & view exhibition/ posters | | |
| Launch of a new model of integrated children's palliative care delivery across Lancashire and South Cumbria | | |
| 14.00-14.05 | Welcome back | Professor Sir Alan Craft |

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| 14.05-14.30 | Reaching families from ethnic minority backgrounds | Lis Meates, Director of Service Delivery & Development, Forget Me Not Children's Hospice |
| 14.30-15.00 | Babies with palliative Care Needs | Dr Cheryl Battersby, NIHR Clinician Scientist, Clinical Senior Lecturer Neonatal Medicine, Imperial College London and Honorary Consultant Neonatologist, Chelsea and Westminster Hospital |
| 15.00-15.30 | Afternoon Break | |
| 15.30-16.30 | 1. Abstracts: Providing family support | 14. This isn't going to hurt. Julia Gibson-Cranch, Locality Wellbeing Lead, EACH. 30. Developing a tool to support the contextualised assessment of medically complex paediatric palliative care patients across settings. Lucy Butters, Registered Nurse, Helen & Douglas House 33. Developing an online feel-good resilience group. William Makenzie, Advanced Practitioner, Rainbow Trust. |
| | 2. Abstracts: Family Experiences of Care | 35. Understanding parent experiences of end of life care for children: a systematic review and qualitative evidence synthesis. Laura Barrett, Research Associate, University of York. 36. A systematic review of the experiences of caregivers and families of children with mucopolysaccharidosis. Dr Joe Clarke, Consultant Paediatrician, Western Health & Social Care Board. A parent's experience Dan McEvoy (TBC). |
| | 3. Abstracts: Workforce | 16. Mapping the paediatric workforce providing palliative care in a large region in England. Dr Archana Soman, Consultant Paediatrician, Sheffield Children's Hospital/ Bluebell Wood Children's Hospice. 25. The value of the senior specialist pharmacist role in a new regional paediatric palliative care service. Stephanie Smith, Senior CPC Pharmacist, Cambridge University Hospital. 37. A collaborative approach for the delivery of palliative care services - Hospice Advanced Clinical Practitioners establishing hospital in-reach services. Lynn Grayson, Director of Clinical Services, Derian. |
| 16.30-16.40 | Move Rooms | |
| 16.40-17.00 | Celebration of 40 years of Helen & Douglas House | Clare Periton, CEO, Helen & Douglas House |
| 17.00 | Chair's wrap up and close | Professor Sir Alan Craft |

DRINKS RECEPTION IN DEANSGATE LOBBY

Day 2: Chair: Dr Hilary Cass

| Time | Title | Speaker |
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| 09.00-09.10 | Chair's Opening | Dr Hilary Cass OBE, Chair, Together for Short Lives |
| 09.10-09.40 | Shifting public understanding of children's palliative care | Nicky Hawkins, Director of Communications and Chiara Vare, Project Manager, On Road |
| 09.40-10.10 | Being present when a child is dying | Tara Kerr-Elliott, Children's Palliative Care Nurse Specialist/ Educator / NIHR Clinical Doctoral Nursing Fellow, GOSH Paediatric Bioethics Service |
| 10.10-10.30 | Communicating with parents following the death of a child | Jeannette Littlemore, Professor of Applied Linguistics at the University of Birmingham & Sarah Turner, Assistant Professor of Stylistics at Coventry University |
| 10.30-11.00 | Morning break & exhibition/poster viewing | |
| 11.00-12.15 | 1. Workshop. | Role of the MDT in complex symptom management. Dr Sat Jassal MBE, Editor of the Symptom Control Manual. |
| | 2. Workshop. | Working with the media. Reframing children's palliative care and how the media talk about it. Nicky Hawkins, Director of Communications and Chiara Vare, Project Manager, On Road. |
| | 3. Workshop. | The Role of the Medical Examiner Dr Luke Smith, Medical Examiner, Guy's & St Thomas' NHS Foundation Trust |
| 12.15-13.15 | Lunch & exhibition/poster viewing On Road lunch drop-in session & meeting the journalists Q&A | |
| Ha13.15-13.20 | Welcome back | Dr Hilary Cass |
| 13.20-13.30 | Parent perspective on Advance Care Planning | Hayley Smallman, Parent |
| 13.30-13.50 | Developing a National Advance Care Plan | Dr Ross Smith, Consultant in Paediatric Palliative Medicine, Leeds Teaching Hospital NHS Trust /Martin House Children's Hospice |
| 13.50-14.10 | What does 'good' palliative care look like for children and young people? | Dr Julia Hackett, Research Fellow & Public Involvement Lead, Martin House Research Centre, University of York |
| 14.10-14.30 | Panel Discussion | |
| 14.30-15.00 | Afternoon break & exhibition/poster viewing | |
| 15.00-16.00 | 1. Workshop: Helping children and young people through conversations about grief and loss. | Amy Smythe, Founder and Chief Storyteller, The Worry Wizard |
| | 2. Abstracts: ACP & communication with families | 32. Understanding advance care planning: a survey of healthcare professionals in Northwest England. Dr Ben Hughes, Lecturer in Health & Social Care, University of Bolton. 39. Lost in translation: A case study exploring effective working with interpreters in paediatric palliative care. |

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| | | <p>Dr Jennifer Melville, Clinical Psychologist, East London Diana Team.</p> <p>40. Ehealth, communication and the delivery of person-centred care for children with life-limiting conditions - what works, for whom, and why? Dr Nicky Harris, Research Fellow, Realist Methodology, Centre for Health and Clinical Research, University of the West of England, Bristol.</p> |
| | <p>3. Abstracts: Staff support, education and training</p> | <p>1. Neonatal palliative and end of life care (NPELC): developing staff skills through simulation education. Dr Jennifer Peterson, Neonatal trainee, Manchester University Foundation Trust</p> <p>26. Unlocking the potential of simulation in promoting confidence in staff in a children's hospice - a pilot project. Rebecca Whiting, Practice Education Facilitator, Shooting Star</p> <p>12. How do children's nurses working in hospices manage emotional labour and professional integrity in long-term relationships with parents? Dr Mandy Brimble, Senior Lecturer, Cardiff University</p> |
| 16.00-16.10 | Short break to move rooms | |
| 16.10-16.45 | Supporting bereaved families with music | KIKI DeVille, Music Therapist, Derian House with families |
| 16.45-17.00 | Chair's wrap up & prize giving | Dr Hilary Cass |