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Paediatric palliative care in the primary care setting: How Specialist Palliative Care can help.

Dr Lynda Brook

Macmillan Consultant in Paediatric Palliative Care

Alder Hey Children's Hospital

Dr Satbir Singh Jassal

Medical Director

Rainbows Children's Hospital

The average a GP will provide end of life care to a child dying at home only two or three times in his or her entire career. It is therefore not surprising that the possibility of having to provide direct support paediatric palliative care at home is viewed by many as difficult and anxiety provoking.

This presentation will review the three tools developed for the End of Life Programme for adults: The Liverpool Care Pathway for the Dying, the Gold Standards Framework and the Preferred Priorities for Care Document. We consider the relevance of each of these tools to paediatric palliative care. We then present examples of how these tools have been adapted for use in paediatric palliative care emphasising the similarities and important differences between their application in paediatric versus adult end of life care.

Providing end of life care to a child dying at home is an unusual challenge for most General Practitioners. However remembering the basic principles of good palliative care and adapting familiar end of life care tools can do much to alleviate this anxiety and ensure that every child dying at home receives the best possible end of life care: getting it right first time, every time.

I am a full time senior partner general practitioner and medical director of Rainbows Children's Hospice in Loughborough, Leicestershire and have worked in children's palliative care for 16 years. I have written and edited the Rainbows Children's Hospice Symptom Control, am an editor of PaedPalLit an abstract journal and have written the chapter on team working in the Oxford Textbook of Paediatric Palliative Care for Children. I am Have just finished co-writing the Oxford Handbook of Paediatric Palliative Medicine. I am co-chairing the education and training subgroup of the BSSPM and ACHDoc. I have a very tolerant wife and two even more tolerant children

Dr Lynda Brook

MBChB, FRCPCH, MSc, Dip Pall Med, Dip Ethics
Macmillan Consultant in Paediatric Palliative Care
Alder Hey Children's Hospital
Liverpool

Lynda.Brook@RLC.NHS.UK

Lynda was appointed as Macmillan Consultant in Paediatric Palliative Care at Alder Hey Children's Hospital Liverpool in June 2003. She is Chair of the Merseyside and Cheshire Children and Young People's Palliative Care Clinical Network Group and Chair of the Northwest Region Children's Palliative Care Network. Lynda is also Chair of the British Society for Paediatric Palliative Medicine (the Royal College of Paediatrics and Child Health Paediatric Palliative Medicine Special Interest Group) and has been a trustee of Claire House Children's Hospice since 1999.

Lynda was one of the working party involved in the development of the ACT (Association for Children with life limiting conditions and their families) Framework for the Development of Integrated Multi-Agency Care Pathways for Children with Life-threatening and Life Limiting Conditions. She has also contributed a chapter for the Oxford textbook of Paediatric Palliative Care.

Lynda is currently leading on the development and implementation of the Liverpool Care Pathway for the dying Child with Professor John Ellershaw and his team. She has also been involved in local work developing advance care planning for paediatric palliative care. She is working with Dr Kerri Thomas, and the Pan Birmingham Paediatric Palliative Care Network undertaking exploratory work prior to the development and implementation of the Gold Standards Framework for Children.