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The tension between the desire to sustain life and the acceptance of death

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Palliative care for (fetus, neonate or infant) with life threatening conditions is an active and total approach to care, from the point of diagnosis or recognition, throughout the child's life, death and beyond. It embraces the physical, emotional, social and spiritual elements and focuses on the enhancement of quality of life for the (neonatal infant) and support for the family. It includes the management of the distressing symptoms (provision of short breaks) and care through death and bereavement. Palliative care requires a holistic approach by the multidisciplinary team who care for the neonate and his/her family. Palliative care planning involves professionals from midwifery, fetal medicine, obstetric, neonatal, community and children's hospice service, and families. Care provision may vary up until the end of life and there may be transition into and out of active supportive and end of life care. The transition from active care for the neonate to palliative care involves an emotional journey for parents and family. The focus of this talk is on the resultant tension between the desire for life and the acceptance of death. Where death occurs within a short time frame there may be little time for parents to process the events and the accompanying emotional journey. Parents require time to process the events, the death of their baby and the assimilation of the new reality. Bereavement follow-up and counselling support need to be timed to coincide with the parents' requirements.

Biography

Mary Goggin works as a Practice Educator at St. George's University Hospitals, NHS Foundation Trust in London, UK. She has lead responsibility for the training and continuing education of staff new to specialty. She has devised a university Work Based Learning programme to ensure consistency in knowledge and clinical standards. Areas of research include the impact of continuing professional knowledge and competence and loss of a twin. She completed her PhD from University of Brighton. She has presented national and international conferences and is a reviewer of reputed journals.

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