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Plenary 3: A Toolbox for the Ethics of Home Ventilation for Children

Abstract

Home ventilation describes the provision of respiratory support to augment breathing with the aim of supporting a patient to live their life at home. This can be done 'non-invasively' by various types of mask applied to the face, or invasively through a tracheostomy. Patients requiring this most commonly have neuromuscular weakness (eg muscular dystrophy) or disorders of pulmonary mechanics (eg scoliosis), but increasingly lung and airway diseases (eg chronic neonatal lung disease). The concept seems simple (keep the child alive), the aim straightforward (live life at home) and the ethics straightforward (promote best interests). However, the simplicity is a fantasy as 'real' people are involved (the patient, parents, family, healthcare providers), the clinical situation rarely static and there are systems (healthcare, community, social) that are not accommodating to these patients. How should we proceed? Bioethics has a role in supporting clinicians, families and patients to think through these issues. There are many ethical tools we must draw on; no single tool is enough to construct the project of getting the child home on ventilatory support. We must be clear about the values of the child and family in order to set the goals of care we are seeking to achieve. We can draw on quality of life considerations and think about patient and family centred care. Shared decision-making forms the scaffolding for deciding to embark (or cease) home ventilation. Since many children requiring ventilatory support are young or disabled, and invariably will be cared for at home by their parents, the zone of parental discretion may be helpful in thinking through the complexities. In the end (or actually the beginning!) is the fundamental question, "what's in it for the kid?"

Biography

John graduated from the University of Sydney in 1990. He trained in paediatrics at The Royal Alexandra Hospital for Children (Sydney) and completed his fellowship in paediatric respiratory medicine at the Children's Hospital Westmead (Sydney) and Royal Children's Hospital (Melbourne). John undertook a PhD at the University of Sydney (1999), "The Early Diagnosis of Cystic Fibrosis". He has been a consultant in the Department of Respiratory Medicine, Royal Children's Hospital (RCH) since 1999.

John is an honorary Clinical Associate Professor in the Department of Paediatrics, University of Melbourne and a Research Fellow at the Murdoch Childrens Research Institute. John is the deputy chair of the RCH Clinical Ethics Committee.