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Transition of patients with neuromuscular disease and chronic ventilator-dependent respiratory failure from pediatric to adult pulmonary care

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Abstract

Improvements in medical care have allowed many children with neuromuscular disease and chronic respiratory failure to survive into adulthood. There are currently no published guidelines to facilitate transition from pediatric to adult respiratory care in this population. The transition process in neuromuscular disease and chronic respiratory failure is uniquely challenging in that the patients are often declining in health and losing independence as they approach adulthood. Barriers to transition include lack of access to adult providers, incompatible health insurance, loss of resources within patients' medical structures, absence of transition preparation, and patient and family insecurity with a new healthcare system. The six core elements and optimal time frame of transition should be applied, with special consideration of the psychosocial aspects associated with neuromuscular disease. Successful transition revolves around information, open communication between young adults and their medical care team, and individualized planning to ensure optimal health and quality of life.

Keywords: Mechanical ventilation; Noninvasive ventilation; Tracheostomy; Transition medicine.

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