

Preface

Children with chronic respiratory failure are living longer, healthier lives than ever before due to advances in medical care, respiratory-related technologies, and respiratory equipment for home use. Over the last several decades, emphasis on the importance of family and community in the care of children with special healthcare needs has resulted in a major shift from institutional/residential care settings to long-term care in the home. Very few children with chronic medical conditions and special healthcare needs are more complex and challenging than children with chronic respiratory failure, who often are dependent for life support on mechanical ventilation. The precise number is unknown, but it has been estimated that thousands of children receive home mechanical ventilation in the United States and the prevalence of home mechanical ventilation for children is likely to be similar in Europe and elsewhere [1].

Children with disorders leading to respiratory insufficiency can be supported in the home with invasive or noninvasive ventilator support. These children often have multiple medical problems, they are supported by complex equipment, and their high risk of complications demands the constant attention of caregivers. Families are faced with a herculean task, made more challenging by the lack of care coordination, lack of expert practice guidelines, and wide variations in practice. At the time of this writing (2016), there are no evidence-based guidelines for the care of children on home mechanical ventilation, and overall the quality of evidence provided by the scant research literature in this area is poor. In addition to a lack of research-derived guidelines for this population, there is also no comprehensive information resource covering all relevant aspects of pediatric home ventilator management.

The goal of this book is to provide, based on literature review and the extensive experience of the expert authors, a single volume with chapters covering all major aspects of caring for children on home mechanical ventilation. In a very real sense, this book is intended to fill a gap until research is sufficient to provide high-quality, evidence-based practice guidelines. Unfortunately, given the profound lack of high-grade research studies in this area, it clearly will be many years and perhaps more than a decade before evidence-based guidelines are even possible. In the meantime,

we hope this volume will be a worthwhile resource for the diverse groups of practitioners who care for these children, including nurses, respiratory therapists, discharge planners, social workers, physicians, and others. It is intended to be useful, not only for pediatric pulmonologists but also for pediatric intensivists, cardiologists, physical medicine/rehabilitation specialists, and the primary care physicians involved in the complexities of managing care for this unique group of special needs children.

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1. King AC. Long-term home mechanical ventilation in the United States. *Respir Care*. 2012;57:921–930; discussion 930–922.

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