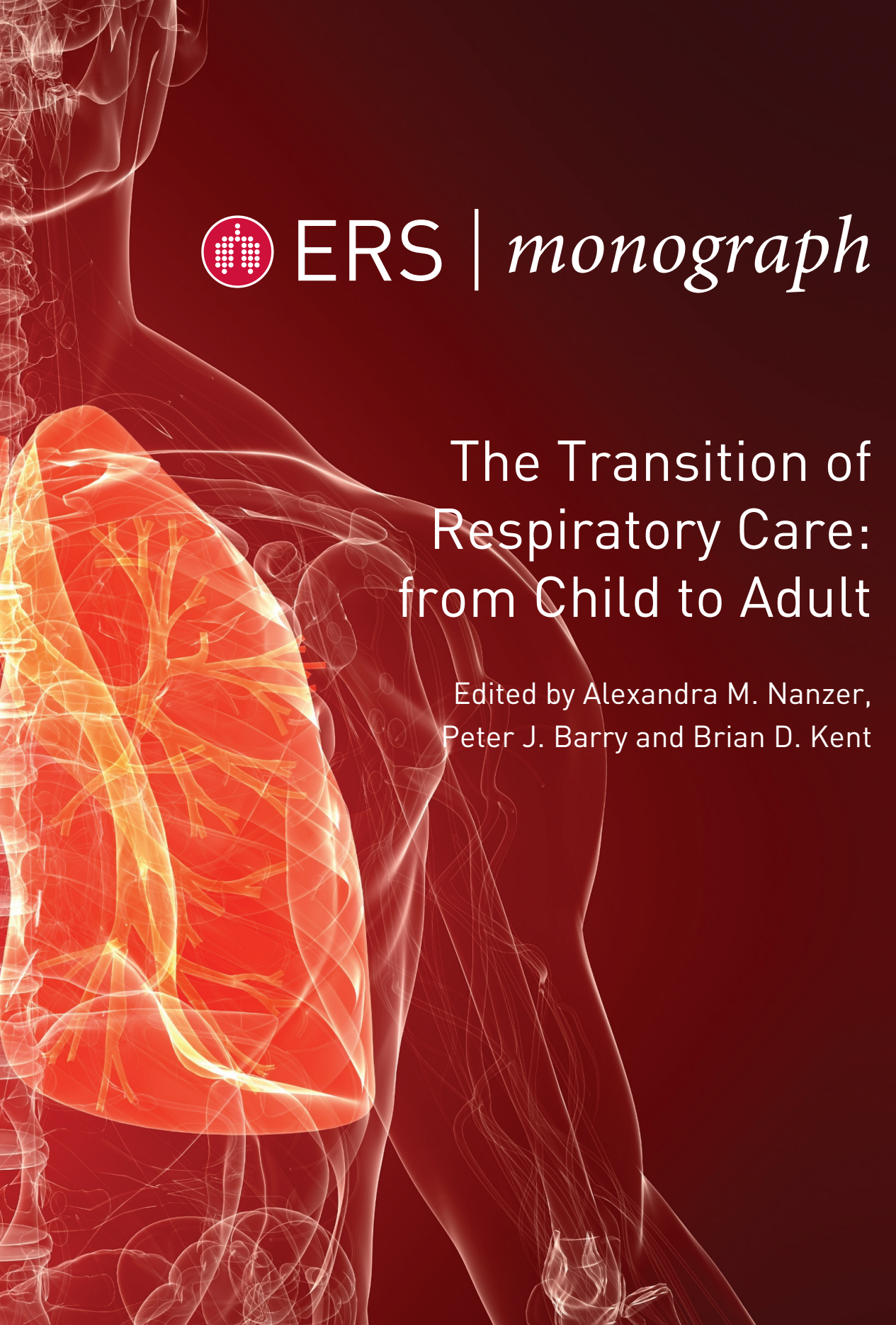

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The Transition of Respiratory Care: from Child to Adult

Edited by Alexandra M. Nanzer, Peter J. Barry and Brian D. Kent

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Editor in Chief
Peter M.A. Calverley

This book is one in a series of *ERS Monographs*. Each individual issue provides a comprehensive overview of one specific clinical area of respiratory health, communicating information about the most advanced techniques and systems required for its investigation. It provides factual and useful scientific detail, drawing on specific case studies and looking into the diagnosis and management of individual patients. Previously published titles in this series are listed at the back of this *Monograph*.

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Contents

The Transition of Respiratory Care: from Child to Adult

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Preface

Peter M.A. Calverley

In 1802, William Wordsworth, who lived not far from where I am writing this Preface, published a poem called “My Heart Leaps Up”. This well-loved and oft-quoted poem contains the line “The Child is the Father of the Man” whose self-evident truth we can all acknowledge, especially if you work in the field of adult obstructive lung disease.

The need to care for the well-being of children had been recognised some 60 years before the poem was written, by a retired sea captain, Thomas Coram, who opened the Foundling Hospital not far from the current Institute of Child Health at University College London (London, UK). Its aim was to care for the increasing number of abandoned children in a rapidly industrialising city. The diseases they tried to treat at the hospital – measles, smallpox and tuberculosis – were similarly prevalent in adults, and it was not until the mid-19th century that separate children’s hospitals were established across Europe and North America. By the middle of the 20th century, it was clear that paediatrics was an important discipline, separate from adult medicine, with a particular expertise that prolonged life and lessened suffering.

Ironically, the substantial gains in quality and duration of life seen in paediatric asthma, cystic fibrosis and neuromuscular disease have made it essential to reopen the dialogue between paediatricians and adult physicians and ensure that patients can move from one system of care in which they have grown up, to another one where they will be managed in future. The fact that this occurs during adolescence only increases the need to do this in a sensitive and appropriate way.

The last 25 years have seen significant advances across a number of disciplines that help the younger respiratory patient navigate this journey. However, this information is not usually available to be consulted in one place. One of the joys of editing the *ERS Monograph* is when enthusiastic guest editors make a proposal for an important topic that we are well placed to address. That is what happened when Alexandra M. Nanzer, Brian D. Kent and

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Peter J. Barry approached us – and this is the resulting volume. They and their expert contributors have done an excellent job explaining the background to transition in care and illustrating the challenges this poses for a variety of young respiratory patients. There is much to stimulate and inform the reader in this volume, which I hope you will enjoy reading as much as I have.

Disclosures: P.M.A. Calverley reports receiving grants, personal fees and non-financial support from pharmaceutical companies that make medicines to treat respiratory disease. This includes reimbursement for educational activities and advisory work, and support to attend meetings.

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Alexandra M. Nanzer is a Consultant Respiratory Physician at the Severe Asthma and Eosinophilic Lung Disease Centre of Guy's and St Thomas' NHS Hospital (London, UK) and a Senior Lecturer at King's College London (London). She obtained her PhD in asthma immunology at the School of Immunology and Microbial Sciences at King's College London.

Alexandra leads the Asthma Transition Service for the South-East England network, holding monthly joint clinics with her paediatric colleagues in the surrounding paediatric asthma centres. She has led projects supporting general practitioners caring for adolescents with asthma, and she oversees Guy's multidisciplinary clinic for adolescents and young adults with asthma.

Alexandra is an Invited Reviews Section Editor at *CHEST* and has published widely in the field of severe asthma, including contributing a chapter to the *ERS Monograph* on Eosinophilic Lung Diseases.

Peter J. Barry

Peter J. Barry is a Consultant Respiratory Physician at Manchester University NHS Foundation Trust (Manchester, UK). He has a clinical and research interest in adult cystic fibrosis and non-cystic fibrosis bronchiectasis. His research interests particularly address the clinical application and outcomes of cystic fibrosis transmembrane conductance regulator modulator therapies.

Peter graduated from University College Cork (Cork, Ireland) in 2002 and trained in Respiratory and General Internal Medicine in the Republic of Ireland, obtaining his Certificate of Completion of Specialist Training (CCST) in 2012. He completed an MD in adult cystic fibrosis at St Vincent's University Hospital (Dublin, Ireland). In 2012, he travelled to Manchester for a post-CCST fellowship, staying on as a consultant at the Manchester Adult Cystic Fibrosis Centre based in Wythenshawe Hospital, which is one of the largest adult cystic fibrosis centres in the UK.

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Peter has served as national and global lead on multiple clinical trials in cystic fibrosis. He is on the committee of the UK Cystic Fibrosis Medical Association and has, in the past, lead the Pulmonology, Immunology and Inflammation Assembly of the European Cystic Fibrosis Society's Scientific Committee. He has served as a clinical expert on National Institute for Health and Care Excellence (NICE) evaluations of cystic fibrosis transmembrane conductance regulator modulator therapies and is a regularly invited speaker at international conferences.

Brian D. Kent

Brian D. Kent is a Consultant Respiratory and Sleep Physician at St James' Hospital (Dublin, Ireland).

A graduate of Trinity College Dublin, he completed specialist training in respiratory medicine in Dublin, before undertaking a 3-year Health Research Board-funded research training fellowship in sleep medicine. Following this, he was appointed as a consultant in respiratory and sleep medicine at Guy's and St Thomas' Hospital (London, UK) in 2013. Over the following 6 years, he helped build one of Europe's largest multidisciplinary sleep services, and also established one of the largest severe asthma services in the UK, before returning to St James' Hospital in 2019.

Brian's clinical practice encompasses the full range of physical sleep disorders (from obstructive sleep apnoea through parasomnia to narcolepsy) as well as the care of people with difficult and severe asthma, alongside other respiratory diseases.

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Introduction

Alexandra M. Nanzer[1], Peter J. Barry[2] and Brian D. Kent[3]

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This *Monograph* emphasises the ongoing need for vigilance in adapting healthcare practices to meet the latest progress in respiratory medicine and the shifting dynamics of adolescents' health needs https://bit.ly/ERSM104intro

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Advances in medicine over the past century have led to increased survival of children with chronic diseases. Historically, parent disciplines such as paediatrics or internal medicine have accorded minimal attention to adolescent patients. But with up to one in five adolescents currently requiring special healthcare needs, and one in 10 facing limitations in daily activities due to chronic illnesses or disabilities [1], specialist care that is "adolescent nedicine" and "Transition of Care" has become more important than ever. The ever-changing societal landscape and multifaceted psychological aspects of adolescence, young people's quest for independence, exploration, and peer influence, contribute to the complexity of managing any long-term illness. Recognising AYA as a distinct patient population with unique healthcare needs, we felt it appropriate to dedicate a *Monograph* to this area.

The book's first chapter explores the evolution of adolescent health as a unique and emerging subspecialty and emphasises the importance of early intervention and collaborative efforts between pediatric, adolescent and adult services [2]. It reviews the advances in the physical and mental health of adolescents, as well as the cultural and societal changes that impact on them, stressing the ongoing need for vigilance in adapting healthcare practices to the evolving movements of adolescents. The chapter adds a strong voice to the case of adolescent medicine as a dedicated medical specialty.

Health inequality has become a buzzword in policy discussions and the COVID-19 pandemic has catapulted the catastrophic consequences of inequality onto our screens and into our minds. What health inequalities means for AYA is a little less clear but there is little doubt that certain social determinants, such as economic status, education, employment, housing and transport are particularly influential in shaping young people's health. Hagell and McKeown [3] discuss this in more depth in chapter 2: "Health inequalities and the social determinants of adolescent health".

Inequality is intricately linked with obesity and the last decade has seen an alarming rise in obesity rates in AYA. This increase has led to a surge in the morbidity and health burden of ever-younger people and has, consequently, become a driving force behind the emergence of adolescent medicine. The chapter on obesity by Brandreth *et al.* [4] therefore felt essential.

We then turn our attention to the psychology of the adolescent mind in chapter 4 [5], followed by a chapter on adherence to treatments in adolescents [6].

The title of chapter 4 – "I just want to get on with my life" – is a quote from a young adult patient, which perfectly expresses the desire for normality in what are immensely challenging years of cognitive and emotional development and the exploration of an individual's roles and responsibilities within society. Stewart-Knight and Carroll [5] summarise key adolescent psychology concepts and literature, with a focus on helping medical professionals in practice with teenage respiratory patients who are transitioning from paediatric to adult services.

We felt it critical, at this point, to cover treatment adherence. Chapter 5 discusses the barriers young adults may face, resulting in non-adherence to treatment and, consequently, poor health outcome [6]. The chapter also reviews behavioural strategies and individualised patient-centric interventions to improve it.

Next we consider individual respiratory diseases, with chapters on sleep and neuromuscular disorders [7–9], pulmonary vascular diseases [10], asthma [11], CF [12] and non-CF bronchiectasis [13].

The transition to adult services can be particularly daunting for AYA with sleep and ventilatory disorders, as they move away from multidisciplinary teams who may have been handling their care for many years to the often seemingly impersonal world of adult medicine. In chapter 7, Tan and Simonds [8] discuss the challenges of the management of AYA with neuromuscular and ventilatory disorders, whilst in chapter 6, Verhulst *et al.* [7] examine the changing pathophysiology of sleep disordered breathing in this population. The sleep perspective is further considered, as Riha *et al.* [9] look at how the care of AYA with narcolepsy and other hypersomnias evolves as they move into adult clinics.

Pulmonary hypertension and congenital heart disease is an important area to highlight. Douglas and Marino [10] discuss the particular considerations of treating adolescents with pulmonary hypertension and the need for a holistic transition to adult care.

A chapter on transition in CF also felt timely, given the dramatic changes brought about by the advent of transformative CF transmembrane conductance regulator modulator therapies. Connett [12] highlights how transition in CF care can be seen as a model for other respiratory conditions and how this is evolving due to the improved health of those with CF.

We felt it important to include a chapter on bronchiectasis that is not due to CF. Chapter 10 comprehensively identifies the needs of patients whose disease can result from a diverse range of pathologies [13].

Asthma is the most prevalent chronic respiratory disease both in children and adults [14]. Chapter 12 by Sánchez-García *et al.* [11] discusses the challenges of adolescent asthma, longitudinal phenotypes, treatments and the opportunities of eHealth and medical artificial intelligence to support AYA during the transition process.

The adolescent voice holds profound importance in shaping policies and interventions that directly impact their lives. Young people's unique perspectives, experiences and insights are invaluable for understanding their needs and preferences in healthcare, education and society. We conclude with a chapter on the patient perspective of the transition between paediatric and

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adult care across the spectrum of respiratory conditions [15]. These narratives were gathered from a range of European countries to represent the variance of experience across the region and highlight patient-centred takeaways on the topic, supported by key findings from the literature and anecdotal narratives from people with a lived experience of transition of care.

We hope that this *Monograph* will offer a useful insight into adolescent health, and we are very grateful to our many distinguished contributors for their help in creating this book.

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List of abbreviations

ADHD	attention deficit hyperactivity disorder
AYA	adolescents and young adults
BMI	body mass index
CF	cystic fibrosis
COVID-19	coronavirus disease 2019
CYP	children and young people
FEV_1	forced expiratory volume in 1 s
HCP	healthcare professional
NIV	noninvasive ventilation