

SECOND EDITION

NURSING CARE OF CHILDREN AND YOUNG PEOPLE WITH LONG-TERM CONDITIONS



EDITED BY
MANDY BRIMBLE | PETER McNEE

WILEY Blackwell

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*This book is dedicated to all children and young people
with long-term conditions and their families*

Nursing Care of Children and Young People with Long-Term Conditions

Second Edition

Edited by

MANDY BRIMBLE

RN, Dip. HE (Child), B.Sc. (Hons)

Community Health Studies (Public Health Nursing/Health Visiting), Registered Nurse Prescriber, PGCE, M.Sc.

Education

Senior Lecturer, Children and Young People's Nursing
School of Healthcare Sciences, Cardiff University, Cardiff,
UK

PETER McNEE

RGN, RSCN, ENB (415), BA (Hons), PGCE, M.Sc.

Senior Lecturer, Children and Young People's Nursing
School of Healthcare Sciences, Cardiff University, Cardiff,
UK

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Contributors

Angharad Dwynwen Barklam, RN(Child), BN (Child), Post Graduate Certificate in Education for Healthcare Professionals

Dwynwen is a Lecturer within the Children and Young People's Team at the School of Healthcare Sciences, Cardiff University. Prior to this she worked as a Practice Facilitator. Her role there comprised of training registered nurses to be mentors to student nurses and providing support to mentors when students are on placement. While working as a registered children's nurse, Dwynwen spent time working on the oncology unit and the medical unit in Noah's Ark Children's Hospital for Wales, where she had the opportunity to develop a keen interest in conditions within specialist fields such as oncology, gastro, neuro, respiratory, endocrine and metabolic as well as general medicine and safeguarding. Dwynwen is currently undertaking her Masters in Education for Healthcare Professionals.

Siân Bill, SRN, RN (Child), DNsg (CU), MN (Melb.), BN (Deakin), Grad. Dip. Adolescent Health (Melb.), Grad. Dip. Education & Training (Melb.), Grad. Dip. Nsg (Infant Child and Youth Health) (UWS)

Siân is a Lecturer within the Children and Young People's Team at the School of Healthcare Sciences, Cardiff University. Her main interests are in adolescent chronic illness, in particular cystic fibrosis, and in transitional care. Siân has worked extensively with young people in both the acute care and community setting. Siân has recently completed her Doctoral studies, which focused on the experiences of young people with cystic fibrosis and

parents transitioning from child to adult healthcare services in Wales.

Mandy Brimble, RN, Dip. HE (Child), BSc (Hons) Community Health Studies (Public Health Nursing/Health Visiting), Registered Nurse Prescriber, PGCE, MSc Education

Mandy is a Senior Lecturer in the Children and Young People's Team, School of Healthcare Sciences, Cardiff University. She has worked as a children's nurse in general medicine, day surgery, at a special children's centre and as the research and education lead in a children's hospice. She has an interest in a wide range of medical and surgical conditions as well as a specific interest in all aspects of safeguarding children and young people. Her training and work as a health visitor has fostered a keen interest in public health and health promotion, particularly childhood accident prevention. Mandy is currently undertaking a Professional Doctorate. Her research project aims to explore long term relationships between children's nurses and parents in the hospice setting.

Dawn Daniel, RN (Child), BSc Community Health Studies (Children's Community Nursing), PGCE

Dawn is a Practice Development Nurse at Cwm Taf Morgannwg University Health Board. She has worked as a lecturer in children's nursing, children's nurse in children's surgery, children's high-dependency nursing and children's community nursing.

Dawn has an interest in children's community nursing and the care of children with long-term conditions. Dawn is currently studying an M.Sc. in Education at Cardiff University.

Jane Davies, RGN, RSCN, Dip. app SS (Open), BSc (Hons), PGCE, LLM, PhD

Dr Jane Davies is a Senior Lecturer in Children and Young

People's Nursing, School of Healthcare Sciences, Cardiff University where she has held a number of senior roles. Jane has made a significant contribution to the development of simulated skills teaching in children and young people's nursing across the UK. Jane is a Florence Nightingale Scholar, has been awarded a visiting researcher residency at the Brocher Foundation, Geneva and was the recipient of a European Oncology Nursing Travel Award. Jane has recently completed a National Postdoctoral Fellowship awarded by RCBC Wales exploring the needs and role of partners when adolescents and young adults have cancer. Currently, her work involves a research grant from Tenovus Cancer Care, to find out more about the information needs of adolescents and young adults returning to work and education following cancer treatment.

Taryn Eccleston, RCN, BSc Nursing (Child),

PGCertEdTaryn is a children's nursing graduate from Swansea University. She started her career in a children's accident and emergency department in a major trauma centre in London before pursuing a career in critical care. During her time in paediatric intensive care she was privileged to work with and learn from children and families with long term conditions and continuing care needs. Many of these children and families required health education and clinical skills training, which ignited a passion that has greatly influenced her career. On her return to Wales Taryn worked primarily in nurse education as a Clinical Skills Tutor at Cardiff University before taking up her current post in neonatal intensive care.

Amie Hodges, MSc in Clinical Practice (Child), PGCE, BSc (Hons), Dip. Asthma, Dip. Allergy and Immunology, L/PE, RSCN, RGN, PhD

Dr Amie Hodges is a Senior Lecturer in the School of Healthcare Sciences, Cardiff University, she is a sociologist

with a clinical background in both child and adult nursing. Amie's research interests focus around the sociology of health and illness; she uses participatory, visual and creative methods within her work with children, young people and families. Within her research she has used dramaturgy to explore the family-centred experiences of siblings living in the context of cystic fibrosis.

Professor Daniel Kelly, PhD, MSc, BSc, RN, PGCE, FRSA, FRCN

Professor Daniel Kelly has held the Royal College of Nursing Chair of Nursing Research at Cardiff University since 2011. His career has been spent mainly in cancer and palliative care nursing and his Ph.D. was from London University on the impact of prostate cancer on men's lives. His research interests are primarily qualitative, with topics having included cancer and palliative care experiences, cancer in early life, clinical safety and leadership. He has produced over 165 journal publications, 15 book chapters and two books, and has generated over £3M in research income. He was awarded a Fellowship of the Royal College of Nursing of the UK in 2016 for research and international work and was President of the European Oncology Nursing Society between 2015-17. He is a member of the Executive Board of the European Cancer Organisation. He is also a Visiting Professor in Nursing Studies at Edinburgh University and Honorary Professor at the Centre for Targeted Intervention in the Division of Surgery at UCL. He has recently been appointed a Trustee of St Christopher's Hospice in London.

Peter McNee, RGN, RSCN, ENB (415), BA (Hons), PGCE, MSc

Peter is a Senior Lecturer in the Children and Young People's Team, School of Healthcare Sciences, Cardiff University. His clinical background is predominantly within paediatric critical care. His main areas of teaching include

the acquisition of clinical skills, paediatric critical care, safeguarding and acute clinical care. Peter is in the final year of a Ph.D. using a narrative approach to exploring fathers' experiences when their child is born with congenital heart disease.

Martina Nathan, RSCN, RGN, BSc Professional Practice, PGCE, MSc Advanced Practice (Education)

Martina is a Lecturer in the School of Healthcare Sciences, Cardiff University. Her clinical background is predominantly within acute paediatric oncology. She has worked in Ireland, Singapore and Wales. Her main areas of interest are children's and young people's cancer care, higher education and recruitment to undergraduate nursing programmes.

Melda Price, MSc, BSc, (Hons), RGN, RSCN, PGCHPE, Dip. DN

Until very recently, Melda was a Lecturer in Children's Nursing in the School of Healthcare Sciences, Cardiff University, having served children's nursing education for 18 years. This followed a 20-year clinical career in primary, secondary and tertiary children's nursing settings. Her teaching expertise was in the care of children with long-term and complex conditions in the community, with an emphasis on interprofessional collaboration in care. Her research interests are the continuing care needs of children and young people with chronic illness and complex needs, and their families; the developing role of the community children's nurse and their interprofessional working and care management of children with life-limiting and life-threatening conditions.

Sian Thomas, RGN, RSCN, MSc

Sian is Consultant Nurse in Child Health at Aneurin Bevan University Health Board. Prior to this Sian was Senior Nurse at the Community Childrens' Nursing Service. Her

specialist clinical and research interests are children with complex health needs and the use of blended diets. She was RCN Wales Nurse of the Year in 2016 for her work in supporting a child with complex health to receive a blended diet. In 2019, she was awarded a Florence Nightingale Foundation Travel Scholarship to explore the use of blended diets in the USA.

Julia Tod, RGN, RM, RSCN, ENB405/998, BSc (Hons) Psychology, MSc (Health Psychology) PGCE

Julia's clinical nursing practice was mainly in neonatal care in North and South Wales, Glasgow and Nottingham. She is currently a Nurse Lecturer and Programme Manager at Cardiff University. Her areas of interest include childhood bereavement and health behaviour of young carers.

Introduction

Mandy Brimble and Peter McNee

Currently, there are limited books available which analyse the context, theory and practice of nursing children and young people with long-term conditions. This second edition provides a comprehensive and fully updated resource for nursing students and post-registration children's nurses on assessing health needs and delivering care and services holistically within and across a variety of care settings in order to meet the changing needs of children and young people with long-term conditions and their families.

Although each chapter can be read independently, the book is designed to provide a comprehensive insight into the changing health care needs of children and young people with long-term conditions and the implications for delivering nursing care and services to children and young people of several age groups, cultural backgrounds, with differing conditions and in a variety of care settings.

In each of the chapters, individualised case studies and reader activities are used to apply theoretical principles and current evidence to nursing practice. In addition, readers are able to gain a greater understanding of the clinical conditions featured in the case studies, both in relation to development issues and associated care needs.

[Chapter 1](#) revisits the aetiology of long-term illness, examining the genetic basis of children and young people's long-term conditions and certain disabilities as a consequence of hereditary influence, providing an overview of chromosomal anomalies and genetic pathways of inheritance. The latter half of this chapter explores the

differing onsets of long-term conditions, considering prenatal, neonatal and late onset, and their implications for practitioners and care delivery.

[Chapter 2](#) examines some of the current political, economic and social policies that are shaping the context and service delivery for children and young people with long-term illness, and the issues and challenges these bring to managers, practitioners and service users. Particular points discussed include workforce changes, patient engagement and commissioning. Examples of service models and nursing roles are analysed to apply these issues and challenges to nursing practice and demonstrate the changing boundaries of clinical practice, multidisciplinary working and service delivery.

[Chapter 3](#) provides a theoretical basis for the impact of long-term illness on the child and parents, examining in detail some classic and contemporary theories relating to grief, loss, coping and adaptation. Suggestions are made concerning effective care strategies and practices to support and help parents adapt to their child's diagnosis of long-term illness. A clinical case scenario of a girl with type 1 diabetes is used to apply the key principles outlined in the chapter.

[Chapter 4](#) is new for this second edition and specifically examines the impact of having a sibling with a long term condition. Contemporary thinking on the rights and needs of siblings is addressed together with impact of becoming a carer for a member of your family. A case study is used to examine these issues in relation to a baby with cystic fibrosis.

[Chapter 5](#) explores these issues further by examining the particular care needs of a girl with eczema, focusing on the implications for children, young people and their families in their adaptation to long-term illness and addressing the

practical implications of assessing and meeting their physical, psychological and social needs. Interesting discussions include issues around ethnicity, culture, spirituality, social isolation and the use of complementary therapies.

[Chapter 6](#) provides insights into the general principles for the need to inform, educate and promote health to children and young people with long-term conditions and their families as an effective means of empowering them to be 'experts' in their care. Using an asthma case scenario, challenges that may arise due to the receptiveness of children, young people and their families, or their intellectual or resource ability to change behaviour, are considered.

[Chapter 7](#) reviews ethical, legal and professional aspects of nursing children and young people with long-term conditions. Scenarios from other chapters are analysed within a framework of ethical principles to identify potential ethical debates and difficult decision-making that practitioners may encounter. The ethical discussions are applied to the practice situation.

[Chapter 8](#) presents a partnership approach between theory and practice, examining changing service boundaries, nursing roles and relationships with parents in the provision of continuing care for children and young people with long-term conditions and their families in the community. To explore this from a practice perspective, multidisciplinary working, discharge planning and respite care are considered using the case scenario of a Welsh-speaking rurally isolated family with a child with the neuromuscular disorder of Batten's disease. The contemporary issue of blended diet administration via gastrostomy is covered in this chapter.

[Chapter 9](#) recognises the importance of acute emergency care, resulting from illness or an unrelated admission, for children and young people with a long-term illness, and the need to ensure effective services and communication processes. Using an oncological haematological condition, current debates and care practices are explored including the need for alternative admission settings.

The last two chapters of the book are especially devoted to teenagers, an increasingly important issue for nurses to consider due to the increasing life expectancy of children with long-term conditions. [Chapter 10](#) provides a critical analysis of the impact of long-term illness upon development transitions of adolescence and the possible health associated risks and longer-term consequences of these. The implications for practitioners in particular focus on communication, body image, compliance and resilience. [Chapter 11](#) builds upon some of the themes raised in Chapter 10 by exploring further a number of aspects of adolescent development in relation to the planning and delivery of effective transition from child to adult services.

This edited book brings together contributions from a team of experienced academics and lecturers in the Children and Young People's Team at the School of Healthcare Sciences, Cardiff University, practitioners, a practice educator and a nurse consultant.

CHAPTER 1

The Definition and Aetiology of Long-Term Conditions

Siân Bill and Angharad Dwynwen Barklam

Introduction

The intention of this chapter is to help the reader further develop their knowledge and understanding of the genetic basis of children and young people's long-term conditions and certain disabilities as a consequence of hereditary influences. Following an overview of chromosomal anomalies, genetic pathways of inheritance will be defined and illustrated via examples of both sex-linked and autosomal recessive and dominant disorders. This chapter does not intend to provide an in-depth critique on the current ethical debates, research and practice controversies surrounding genetic engineering and modification. For this the reader is guided to websites such as www.bionews.org.uk.

The latter half of the chapter focuses on examining the differing onsets of long-term conditions, considering prenatal, neonatal and late onset. To provide the reader with a practice focus, case studies will be used as examples to examine the professional and care implications of nursing children, young people and their families whose long-term conditions have been diagnosed at various stages of their development. To allow these issues to be further developed and explored, the same case studies will be used in subsequent chapters.

Aim of the chapter

To enhance the genetic knowledge and understanding of nurses, including the aetiology of long-term conditions in children, and to examine how this genetic competence can be implemented in their practice to:

- Lead to a reduced risk of conditions occurring, or a reduction in severity for those where a condition has been identified.
- Enable them to fully participate in the relevant debates and ethical discussions that can have implications for children, young people and their families.

Intended learning outcomes

- To examine the hereditary influences upon the genetic basis of long-term conditions in childhood
- To determine patterns of genetic inheritance
- To investigate the origins of long-term conditions
- To explore the role of the children's nurse during the period leading to, and at the time of, diagnosis

Genetic knowledge

This chapter is written on the assumption that the reader comprehends the basic foundations and principles of genetics. These being: the biology of chromosomes, the structure and role of deoxyribonucleic acid (DNA) in coding genetic information, its ability to replicate and the mechanisms for protein synthesis. In particular, knowledge of the nitrogenous bases and the mechanisms of transcription and translation are required. A good grasp of the cell cycle and its governing control system, along with knowledge of the distinct stages of mitosis and the two