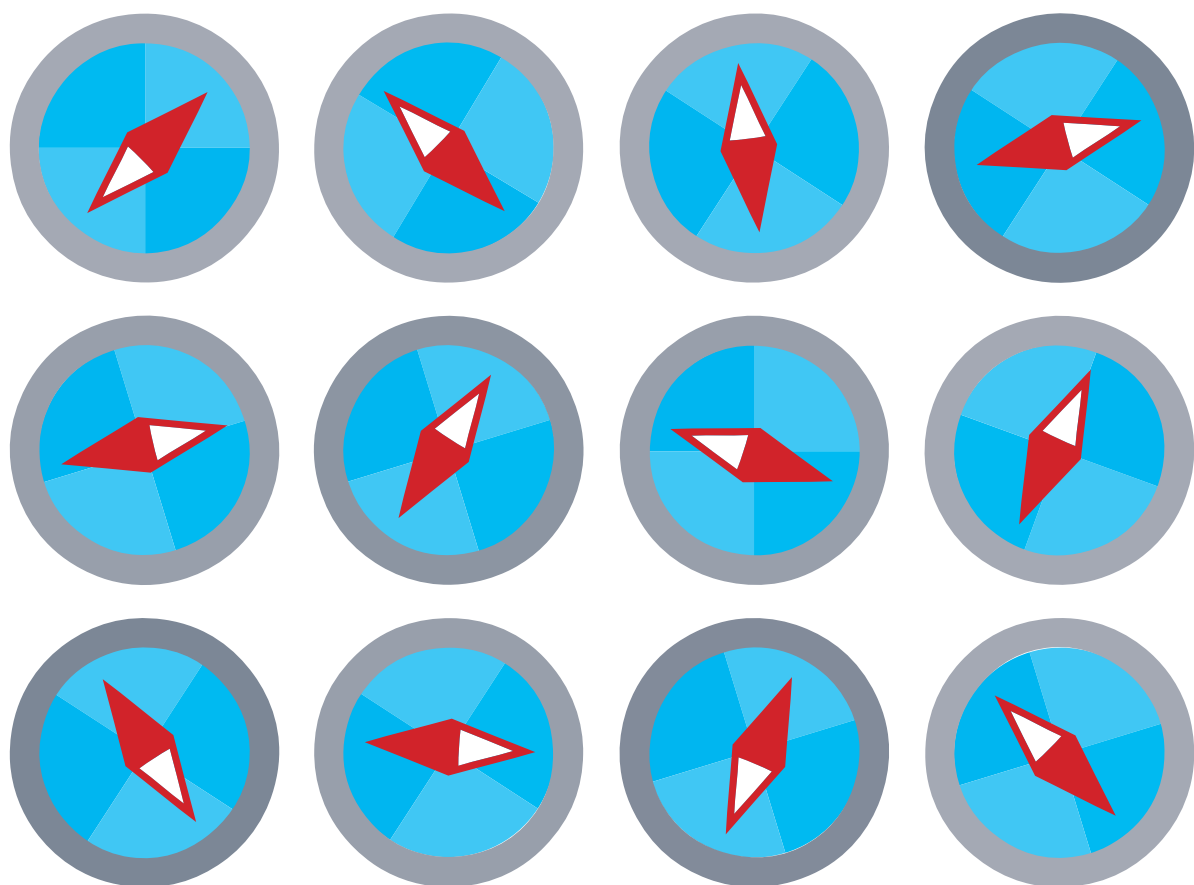


LONG-TERM CONDITIONS

Challenges in Health & Social Care



edited by
Cathy E. Lloyd & Tom Heller



LONG-TERM CONDITIONS

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Challenges in Health and Social Care

Edited by Cathy E. Lloyd and Tom Heller



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This book is dedicated to two wonderful women.

Elizabeth Simmons who bravely fought the debilitating consequences of her long-term conditions for many years and who was a dear friend and inspiration to Cathy Lloyd, and Elisabeth Hudson who was Tom Heller's mother-in-law and who was a role model for him in so many ways.

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Notes on the Editors and Contributors

Cathy E. Lloyd is an academic and researcher at the Open University, where she is a Senior Lecturer in the Faculty of Health and Social Care. She has been involved in teaching pre-registration nursing and courses in health care studies, where understanding the personal experience of long-term conditions is a central tenet. Her current research interests include the experience of co-morbid physical and mental illness, and in particular the impact of the ever increasing burden of diabetes and its psychological sequelae on both an individual as well as societal level. Recently the measurement of psychological wellbeing and the cultural applicability of existing tools to measure psychological distress in minority ethnic groups has been the focus of her funded research, which has led her to international collaborations with colleagues from the Dialogue on Diabetes and Depression (DDD) as well as from the European Association for the Study of Diabetes (EASD) Psychosocial Aspects of Diabetes Study Group.

Tom Heller has had parallel careers as a doctor and as an academic. Both paths have involved attempts to understand the issues and challenges that are faced by people with long-term conditions, their families and their formal and informal carers.

As a doctor he worked as a general practitioner in some of the most deprived areas of Sheffield where long-term illness is ever present and where it has become a major factor shaping the lives of many people living there. His work as an academic has centred around his appointment as a Senior Lecturer in Health at the Open University, Faculty of Health and Social Care, where for the last 25 years he has been involved in writing a wide range of health courses. His interests include mental health, complementary medicine and, of course, the way that long-term conditions affect the lives of people.

Katharine Barnard is a health psychologist at the University of Southampton. She has a longstanding research interest in the psychosocial issues associated

with Type 1 diabetes in children, adolescents, adults and other family members. Through her research she has gained an in-depth understanding of the factors that contribute to quality of life and the impact of diabetes on daily living. The effect of diabetes, both medically and socially in terms of everyday coping, psychosocial impact and psychological burden, is a multifaceted and complex area and Dr Barnard's research to date has made significant advances in the unravelling of these complexities for individuals living with the condition.

Elaine Denny is Professor of Health Sociology at Birmingham City University. She has a background in hospital and community nursing and taught health sociology to students on health related courses for 20 years. Her research interests focus around women as recipients and providers of health care, and she has published work on women's experience of IVF, the experience of endometriosis, and on the occupation of nursing. Elaine has co-authored with Sarah Earle a health sociology text *Sociology for Nurses* the second edition of which was published in 2009. Also with Sarah Earle she has edited *The Sociology of Long-term Conditions*. Recent research includes a NHS Research for Patient Benefit funded collaborative study on endometriosis and cultural diversity aimed at improving services for minority ethnic women. She is also involved in exploring the patient perspective in a number of NHS NIHR funded clinical trials in collaboration with Birmingham Women's Hospital where she is an Honorary Research Associate.

Dr Sarah Earle is a medical sociologist with a special interest in reproductive and sexual health. She convened the British Sociological Association's Human Reproduction Study Group for nearly 14 years and her work spans across the field to include: pregnancy and childbirth, infant feeding, reproductive loss, commercial sex and sexual health services provision. She is currently Senior Lecturer in Health and Associate Dean for Research in the Faculty of Health and Social Care at The Open University. She is Sub-editor for Health and Social Sciences for the journal *Human Fertility*.

Andrew Gibson is a Research Fellow in Patient and Public Involvement (PPI) with the Peninsula Collaboration for Leadership in Applied Health Research and Care (PenCLAHRC). He has experience of evaluating user involvement in a number of contexts and he previously worked at the DH funded National Centre for Involvement at Warwick University. He also has experience of coordinating user involvement in research and teaching in the School of Health and Social Studies at Warwick University. He has responsibility for developing PPI within all the activities of PenCLAHRC.

His other research interests lie in the area of lay perspectives on health inequalities. His research in this area has drawn on the work of Bourdieu to explore the relationship between health, social status and social capital from the perspective of people living in a 'deprived' community.

Alistair Hewison is a Senior Lecturer in the School of Health and Population Sciences at the University of Birmingham. His professional background is in nursing, and he has experience as a staff nurse, charge nurse and manager in the NHS in Birmingham, Oxford and Warwickshire. Having undertaken a number of roles in Higher Education including Head of Nursing and Head of School, his current research and teaching activities are centred on the management and organisation of care. His main focus at the moment is a five year project examining service re-design in three acute NHS Trusts as part of the National Institute for Health Research funded Collaborations for Applied Health Research and Care programme in Birmingham and the Black Country (CLAHRC-BBC). He has written widely on health care management and policy issues in papers published in scholarly journals and chapters in edited collections.

Ruth Howard qualified as a Clinical Psychologist in 1996 and for many years worked in the area of cancer and palliative care, in clinical and academic roles. In 2000 she took up a post on the Clinical Psychology Training Course at the University of Birmingham and progressed to the role of Clinical Director in 2005, and more recently has moved into a Senior Academic Tutor on the course. She continues to work clinically in palliative care, and supervises research in this and other areas of health psychology, and over the last 4 years she has begun to develop research into the psychosocial impact of coeliac disease and its management. In 2008 she was awarded a grant by Coeliac UK to carry out a two-year study into the psychological and social implications of coeliac disease across the lifespan – the first study of its kind in the UK. This has led to the development of further research in this area and the establishment of the Coeliac Disease Research Steering Group at the University of Birmingham.

Mary Larkin is a Principal Lecturer in the Faculty of Health and Life Sciences, De Montfort University. She is also currently Programme Leader for the BA Health Studies and BSc Public and Community Health and has extensive experience of teaching on both undergraduate and postgraduate health and social care courses for a range of students, including health care professionals, in several higher education institutions. Her research interests are carers, carer empowerment adult social care, health and well-being,

disability, and the third sector. She has carried out research at both national and international level as well as published widely about issues related to these research areas. Her publications also include several textbooks on health and social care.

Gary Law qualified as a Clinical Psychologist in 2000 and has worked clinically in the area of child psychology, child mental health and wellbeing for over 10 years. His current clinical post is in a Child and Adolescent Mental Health Service, where he leads the primary care service. In 2002 he joined the Clinical Psychology Training Course at the University of Birmingham and currently works as a Senior Academic Tutor and Lecturer. He contributes to the teaching and research supervision of undergraduate and postgraduate students. His research interests include child and family beliefs regarding chronic physical health and mental health, specifically the use of self-regulation theory to explore self-management and adjustment. Additional interests include the stigma of child mental health and predictors of help seeking.

Sara Mackian is a Senior Lecturer in Health and Wellbeing at The Open University. Formerly Lecturer in Health Geographies at the University of Manchester, the driving theme underpinning her research is a curiosity for how people, communities and organisations interact around issues of illness, health and wellbeing. This has led to a range of studies exploring ME, parenting, sexuality, spirituality and public health. A geographer by training, Sara has a particular interest in qualitative research methodologies, and has developed a method for ‘mapping’ data analysis, which she uses to visualize the worlds of experience revealed through her research, where the physical, socio-cultural, subjective and otherworldly intersect. She is author of *Everyday Spirituality: Social and Spatial Worlds of Enchantment* (Palgrave Macmillan).

Margo Milne is a researcher and a disabled service user living with a long-term condition. Her work includes both qualitative and quantitative research into the experiences of long-term conditions and attitudes towards end of life care, disability and physical illness. Her chapter focuses on the debates surrounding the overlap between disability, physical health and ill health, and the implications for receiving health and social care.

Stephen Pattison is an interdisciplinary scholar who presently serves as Professor of Religion, Ethics and Practice and HG Wood Professor of Theology at University of Birmingham where he is also head of the Department of Theology and Religion. An honorary professor in medical

humanities in the School of Medicine and Health at Durham University, he also sits on the Ethics Committee of the Royal College of General Practitioners. Pattison is a former health care chaplain and consumer champion in the NHS. With interests in applied theology, management, visuality, values and ethics he is one of the co-editors and contributors to *Values in Professional Practice* (2004) and *Emerging Values in Health Care* (2010). Other recent and forthcoming publications include *Seeing Things: Deepening Relations with Visual Artefacts* (2007), *Face: Practical Theological Reflections* (2013), *Muslim Chaplaincy in England and Wales* (2013). Pattison was the founding co-ordinator of Think About Health (www.thinkabouthealth.com), an interdisciplinary reflective group dedicated to doing intellectual plumbing in the NHS.

Jane Petty conducted her PhD at the University of Birmingham with Professor Chris Oliver. The project explored self-injurious behaviour in children with severe intellectual disabilities and was completed in 2006. She then worked with Professor Oliver on a project looking at challenging behaviour in children and young adults with Angelman, Cri du Chat and Cornelia de Lange syndromes; genetic disorders associated with intellectual disability. In 2009, Jane moved into Health Psychology research, taking up a research fellow position with Drs Ruth Howard and Gary Law exploring psychosocial factors in coeliac disease. Her interest in Health Psychology continued to grow and she is currently working towards an MSc in Health Psychology via distance learning. Jane hopes to combine both her areas of expertise in future research and explore psychosocial issues associated with intellectual and physical disability, particularly from the parent/carer perspective.

Terry Pratchett needs no introduction; he is one of the most popular and prolific authors in the UK. He has established himself as a wonderfully resourceful and imaginative writer able to create whole new worlds for his cast of characters to inhabit ... but he now has been given a diagnosis of early dementia. He has 'gone public' about his condition and written articles for the popular press and appeared on television programmes discussing the condition in general and his prospects in particular. In his chapter Terry talks about some of his hopes and fears, as well as his early experiences of living with the condition.

Rachel Purtell is the Folk.us Director with day to day responsibility for Folk.us. This role ensures that service users, patients and carers are able to have a positive and meaningful impact on research, and the structures and

processes that support research in health and social care. Rachel works with many people including people with learning difficulties, people who experienced mental distress, people with physical and/or sensory impairments, older people and people who are long-term users of the NHS. Rachel is a freelance trainer in Disability Equality Issues using a Social Model approach. She holds an MA in Disability Studies. She has a background in working for inclusive service user led organisations and delivers training. Rachel is disabled women, a disability activist and a service user.

Erica Richardson holds an honorary post in the European Centre on the Health of Societies in Transition (ECOHOST) at the London School of Hygiene and Tropical Medicine, while working for the European Observatory on Health Systems and Policies. Her research background is in Area Studies, analysing the development of public health policy and interventions in the field of substance abuse and HIV/AIDS prevention in the Russian Federation. Her current research focuses on health system reform in countries of the former Soviet Union but encompasses broader comparative work on health systems and policies in Europe. The aim of her work at the Observatory is to inform the comparative analysis of health systems and to raise awareness among policy-makers about international experience in health system reform. At LSHTM she teaches on the Masters in Public Health course.

Introduction

Cathy E. Lloyd and Tom Heller

This book has set itself a considerable challenge which is to explore the reality of the lives of people who develop long-term conditions and discuss some of the challenges for people who set out to care for them. The book takes a broad perspective which includes the worlds of both health and social care and contextualizes some of the diverse ways that people live with and experience these conditions.

Increasingly, people in developed countries can expect to live longer and this has important implications for long-term health and well-being. Many of the conditions that previously may have limited the length of a person's life can potentially be controlled and are no longer necessarily life threatening. Growing numbers of people experience more than one long-term condition, and this increasing complexity of need has important implications for both formal and informal types of health and social care provision.

The growing numbers of people in the UK living with long-term conditions has a serious impact on the way that resources within the NHS and the social care services are organized. There are also clear indications that there is a need throughout these services and in wider society for improved education and training for those living with long-term conditions, and also for carers and practitioners. Health and social care practitioners continue to be encouraged to work in partnership with people living with long-term conditions and with their carers. In order to reflect some of these dynamics the contributors to this book include people who identify themselves as having a long-term condition as well as authors drawn from a range of different academic disciplines. The authors have employed a range of research-related perspectives that reflect the need for multi-professional understanding of this complex subject area. Each chapter is based either on personal experience, or on empirical research and critical analysis of current policies and management of these conditions. The aim throughout has been to assist the reader in considering health and social care in context,

bridging theory and practice, and challenging and inspiring current practice in health and social care.

The book is divided into three sections that reflect the different perspectives of a wide range of interested parties. This includes people who use services, carers, practitioners, managers and policy makers. At the same time each chapter uses empirical research to help the reader understand some of the realities associated with the provision of health and social care. The first section – Receiving Care – focuses on services users' experiences of health and social care, and includes the researched experiences of people who have a variety of different long-term conditions including ME, diabetes and Alzheimer's disease. The contributors to this section describe in detail service-users' perspectives on self-management of long-term conditions and the frequently experienced tensions between individual and health service priorities for care. The often unremitting, day to day need for self-care and the incorporation of the needs of illness into daily life is explored and discussed. A wide range of different perspectives and a variety of research methods underpin these chapters. For example in the first chapter Sir Terry Pratchett uses a very personal account that could be described as an auto-ethnographic approach to describe his experience of the early stages of Alzheimer's disease. Subsequent chapters utilize a wide variety of other types of research data, both qualitative and quantitative.

The second section of this book – Working with People with Long-term Conditions – focuses on some of the ways that practitioners and service users may be able to work together in a range of settings in order to improve the lives of people with a variety of long-term conditions. The dilemmas experienced by GPs and other health care workers when faced with difficult decisions in the provision of care are considered. In addition some of the ways that research, and especially service user involvement in research, can inform practice are outlined. This section also includes a consideration of some of the different approaches to disability within the field of health and social care, and the implications for practitioners working with disabled people. Integral to these contemporary issues are debates around partnerships in care, empowering practice, inter-professional working and effective communication in health and social care.

The final section of this book – Delivering Health and Social Care for People with Long-term Conditions – focuses on policy, organizations, and ways in which the complex needs of individuals with long-term conditions are managed across the boundaries of health and social care. The chapters in this section have been designed to give the reader an up-to-date understanding of some of the policy-related debates concerning care provision for people with long-term conditions. Current concerns around

the growing number of people living with long-term conditions and the quality and increasing complexity of care provision are explored. The daunting organizational constraints in delivering care are considered and the implications for future practice discussed. Some of the complex ethical issues involved in delivering care for people with long-term conditions as well as the importance of making a clinical diagnosis and the role of carers in supporting this group of people are also explored.

This book gives the reader a chance to gain an in-depth understanding of the experience of long-term ill-health from a range of perspectives. Together the contributors have provided an opportunity to critically reflect on both the boundaries between health and social care provision, and the importance of evidence in understanding health and ill-health, and learn about current policy drives towards improved inter-professional working. We hope the collection will help people who are service users as well as health and social care practitioners move towards a greater understanding of integrated care, the complexity of needs, and multi-professional working. The various chapters also point to key areas for future research.

This book is the result of many different people's hard work and we would like to take this opportunity to thank them all. In particular a vote of thanks goes to all our colleagues who contributed to this book, to our Editorial Assistant at Sage, Emma Milman, and to Billy Simmons who made many suggestions for the book cover.

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SECTION ONE

RECEIVING CARE

Introduction

Cathy E. Lloyd

People currently living in developed countries can expect to live longer than their predecessors, but at the same time are faced with the likelihood that they will be diagnosed with one or more long-term conditions during their extended lifetime. This has implications for formal and informal health and social care services in these countries because people will increasingly need more care for longer periods of time. Previous research has traditionally been seen from the perspective of health care professionals and has often focused on biomedical cures for disease rather than on ways that people may be able to cope with conditions that are not curable, only manageable. More recently there has been a shift towards research that focuses on managing long-term conditions in order to maintain an acceptable quality of life. This re-focus emphasizes each individual's ability to self-manage their own health and illness. The first section of this book brings together some of this novel research and focuses on personal experiences of long-term conditions and the health and social care that has been received.

The first contribution to this section is entitled 'Living with Early Dementia' from Sir Terry Pratchett. Sir Terry is one of the most popular and prolific authors in the UK. He has established himself as a wonderfully resourceful and imaginative writer able to create whole new worlds for his

cast of characters to inhabit – but he now has been given a diagnosis of early dementia. He has ‘gone public’ about his condition and written articles for the popular press and appeared on television programmes discussing the condition in general and his prospects in particular. In this chapter he talks about some of his hopes and fears, as well as his early experiences of living with the condition.

The following chapters are also from contributors who have experience of particular long-term conditions as well as having conducted research in the field. Margo Milne takes an auto-ethnographic approach in her chapter, ‘Disability and Illness: The Perspectives of People Living with a Long-term Condition’, and combines her own personal experience of multiple sclerosis (MS) with her empirical research into this long-term condition. She asks the question: ‘Is it a physical problem or a disability?’ and debates issues surrounding the overlap between disability, physical health and ill-health, and the implications for receiving health and social care. This chapter contains a consideration of the appropriateness of different methodological approaches to researching these sensitive issues and discusses ways of ensuring that the voices of people living with long-term conditions are heard.

The experience of having a long-term physical condition can be made more complex when other health problems occur at the same time. Having more than one long-term condition, often called ‘co-morbidity’, is the subject of the next chapter by Katharine Barnard and Cathy E. Lloyd. Both these authors have been researching in the field of diabetes and mental health for a number of years and in their chapter they review some of that research. The chapter, ‘Experiencing Depression and Diabetes’, focuses on the experience of having diabetes as well as depression. People with diabetes have to grapple with the heavy, constant burden of having to look after their own condition and it is no wonder that they run a greatly increased risk of developing mental health problems, especially depression. The combination of physical and mental health difficulties often leads to serious challenges for the provision of appropriate care. This chapter reviews some of the empirical evidence of increased rates of depression in people with this long-term condition. More recent research on the impact of self-management on feelings of diabetes distress or ‘burnout’ is also described and discussed. The difficulties for health workers of identifying whether a person with diabetes is feeling depressed, or whether they have become distressed about the management of their diabetes, are also debated.

The chapter entitled, ‘Experiencing and Managing Medically Unexplained Conditions: The Case of Chronic Pelvic Pain in Women’, has been contributed by Elaine Denny. She explores the impact of being

assigned the label of 'unexplained' for women experiencing pelvic pain. This chapter focuses on the concept of 'expert knowledge' and discusses whose knowledge should be considered to be more 'legitimate'. Diagnosis has become an integral element of biomedicine that provides legitimization of symptoms and confers credibility on people who are living the reality of those unexplained symptoms. This is important because without a recognized diagnosis entitlement to services and treatment is open to question. However for many doctors Chronic Pelvic Pain remains a controversial and contested condition. This adds another level of complexity that women with this condition have to negotiate in their passage through the formal health care system.

The final chapter in this section of the book is written by Sara Mackian who is an academic, a researcher, and also a service user with ME. She takes an auto-ethnographic approach in her chapter, 'Me and ME: Therapeutic Landscapes in an Unfamiliar World'. This chapter is underpinned by her empirical research alongside other people with ME. She explores how this condition, for which biomedicine can define no clear cause and currently offers no effective treatment, can leave the individual beyond the safety net of formal service provision. This means that many people find themselves feeling isolated and have to negotiate a 'new normality' which works for them and their condition. ME has serious implications for physical engagement with the world and the condition often leaves people shut off and unable to interact. However, Sara's research investigates some of the creative ways in which people with ME may be able to fashion new subjective, social or spiritual worlds to help them cope with their experiences.

This section of the book brings together research into the way that people living with long-term conditions view the management of their own situation and their health concerns. Much of the empirical evidence cited in these chapters comes from in-depth qualitative research, demonstrating the importance of these methods in understanding individuals' experiences of long-term conditions.

Living with Early Dementia

Sir Terry Pratchett

Overview

- Clapham Junction days
- Obtaining a diagnosis of early Alzheimer's
- Undeniable signs
- Disease of knowledge

People who have dementia in this country are not heard. I'm fortunate; I can be heard. Regrettably, it's amazing how people listen if you stand up in public and give away \$1million for research into the disease, as I have done. Why did I do it? I regarded finding I had a form of Alzheimer's as an insult and decided to do my best to marshall any kind of forces I could against this wretched disease.

I have posterior cortical atrophy or PCA. They say, rather ingenuously, that if you have Alzheimer's it's the best form of Alzheimer's to have. This is a moot point, but what it does do, while gradually robbing you of memory, visual acuity and other things you didn't know you had until you miss them, is leave you more or less as fluent and coherent as you always have been.

I spoke to a fellow sufferer recently (or as I prefer to say, 'a person who is thoroughly annoyed with the fact they have dementia') who talked in the tones of a university lecturer and in every respect was quite capable of taking part in an animated conversation. Nevertheless, he could not see the teacup in front of him. His eyes knew that the cup was there; his brain was not passing along the information. This disease slips you away a little bit at a time and lets you watch it happen.

This is a slightly edited version of an article first published in the *Daily Mail*.