### Fundamental Aspects of Long-Term Conditions

#### Note

Health care practice and knowledge are constantly changing and developing as new research and treatments, changes in procedures, drugs and equipment become available.

The author and publishers have, as far as is possible, taken care to confirm that the information complies with the latest standards of practice and legislation.

# Fundamental Aspects of Long-Term Conditions

A Guide for Students of Nursing and Health

Edited by Helen McVeigh



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### Foreword

Long-term conditions is an extremely important addition to the Fundamental Aspects series. The implication of increasing life expectancy is that many people now live with what have been termed 'long-term conditions'. Most people over the age of 50 years have some form of long-term health problem. For most, this is a relatively minor and easily treatable condition, such as raised blood pressure, some joint pain, eyesight deterioration, or mild diabetes, while for others the condition may be more serious.

Possibly one of the most distinguishing features of any long-term condition is the effect it has on the lifestyle not only of the person with the condition, but their family, friends and colleagues. This is brought out with considerable force in the chapters written by 'patients' and 'carers'. As nurses, so often we only see the immediate medical problem the patient is presenting with, and while that is important in terms of assessment and management, it must not be seen in isolation from the holistic picture, which so often, only the patient is aware of—hence the concept of the 'expert patient'.

In editing this book, Helen McVeigh has brought together a number of clinical specialists, university lecturers, patients with long-term conditions and carers. As you read through individual chapters and then the complete book, you will begin to appreciate not only the medical implications of long-term conditions, but in addition you will gain an insight to what it feels like to be labelled in this way. If you can have some empathy into that experience, then you will be a far more understanding nurse.

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### Introduction

Providing support and care for individuals with a long-term condition is an essential feature of modern health care. Over 15 million people in England currently have a long-term condition, and it is predicted that these numbers will continue to rise (Department of Health [DH], 2008). The impact of long-term conditions will affect every one of us in some way. For many of us this may be first hand as a sufferer, for others it will be in providing care or support to a partner, family member or friend.

The DH defines long-term conditions as 'those that cannot at present be cured but can be controlled by medication or other therapies' (DH, 2007). Living with a chronic illness offers no rosy end-point; unlike acute illness, where full recovery is expected, there is no return to normal health. The length, progress and severity of the illness will mean that the individual has to come to terms with living with their condition. For the individual this will often necessitate lifestyle changes and modifying expectations for the future.

As nurses, our understanding of how a long-term condition influences an individual is often guided by our medical and physical knowledge of disease processes. We need to remember that living with a chronic illness will impact on all aspects of life. There will be significant psychological, social and emotional costs of living with a long-term condition. A holistic nursing perspective acknowledges that practice should be underpinned with a comprehensive understanding of all factors that impact on the quality of life for an individual; physiological, psychological, social, spiritual and environmental. We also need to understand and acknowledge the experiential experiences of the individuals we care for. In addition, nursing practice needs to evolve in response to the changing expectations of individuals, society and healthcare provision. Our success in providing effective and long-lasting quality interventions may well be reliant on successfully balancing our understanding of all these aspects of care.

This book aims to raise your awareness of long-term conditions, their management and the implications of living with chronic illness. The book takes a patient-centred, holistic approach, which aims to help you understand that an individual's response to having a long-term condition is both complex and unique to them. The focus throughout explores long-term conditions in relation to the adult patient. Although some long-term conditions may begin in childhood, the concept of disease management in childhood and the implications this raises is considered to be a separate topic.

Chapter 1 introduces the subject and places long-term conditions in context, and looks at the impact current policy has on healthcare provision. It explores the notion of chronic illness and identifies a framework for management which introduces the concepts of self-care and the expert patient. The themes raised in this chapter are echoed in the approach and structure of subsequent chapters.

The following chapters focus on specific conditions taking a proactive approach that considers management, the role of relevant services, coping strategies, quality of life and self-management. While chapters have focused on individual conditions, it is important to be aware that many individuals may have more than one condition, or indeed complex comorbidities. It is also important to recognize that many conditions will shorten life expectancy and chapter 14 considers the topic of palliative care and end-of-life decisions. The issue of lifestyle choice and the influence this has on both the development of and progress of long-term conditions is of particular relevance. Chapters 12 and 13 explore the issues of obesity and alcohol use, while smoking is discussed within Chapter 5 in relation to chronic obstructive pulmonary disease (COPD).

Management is not just the remit of health care, as living with a long-term condition affects all aspects of a persons' life; home, work, environment, spirituality, and psychological wellbeing. relationships. The 'real life' impact of living with a long-term condition is considered in Chapter 8, which highlights the personal reflection of a patient. Coping with chronic illness impacts on the quality of life of not only the individual concerned and Chapter 9 emphasizes the personal reflection of a carer. A coordinated approach involving the patient, carers, primary care, secondary care, and social care provision is fundamental to effective management strategies and the provision of high quality care that meets the needs of both the individual and communities. Chapter 15 explores the concept of multi-professional collaboration and identifies the myriad of services that are available to support individuals in managing their conditions, while Chapter 16 considers the future and the use of technology in managing and supporting health care.

### Using this book

The chapters of this book have been designed with a structured approach. Chapters are introduced with a list of suggested learning outcomes. Each

chapter highlights the epidemiology and demography of specific conditions and draws attention to relevant policy supporting health care. A needs-led focus on the patient is used, including physical, social, psychological, spiritual, cultural, and environmental issues. Many of the contributors have used case history examples and scenarios to illustrate aspects of need and the issues discussed. Within each chapter, you will find questions related to content and points for reflection.

This book sets a challenge to student nurses and those embarking on their nursing career pathway, that supporting patients with long-term conditions is the responsibility of all nurses. An individualized, person-centred approach is fundamental to care provision. This book should make you think about how you can make a difference in the lives of those managing with a long-term condition. It should enable you to take a holistic perspective in the care, management and support of these patients.

'When you leave the clinic you still have a long term condition, when the visiting nurse leaves your home you still have a long term condition. In the middle of the night you fight the pain alone. At the weekend you manage without your home help. Living with a long term condition is a great deal more than medical or professional assistance.' Department of Health (2005:2).

### References

- DH (2005) Supporting people with long term conditions. An NHS and social care model to support local innovation and integration. DH, London. ref: 4230
- DH (2007) Long-term conditions: Background. http://tinyurl.com/kw6n3v (accessed 15 December 2009)
- DH (2008) *Raising the profile of long term conditions: A compendium of information.* DH, London. ref: 8734