Long-term Conditions

A GUIDE FOR NURSES AND HEALTHCARE PROFESSIONALS

EDITED BY SUE RANDALL AND HELEN FORD

WILEY-BLACKWELL

Long-term Conditions

A Guide for Nurses and Healthcare Professionals

Long-term Conditions

A Guide for Nurses and Healthcare Professionals

Edited by

Sue Randall

RGN, RHV, BSc (Hons), MSc, PGCE (HE)

Senior Lecturer
Pathway Leader Long-term Conditions
Department of Nursing, Midwifery and Healthcare
Faculty of Health and Life Sciences
Coventry University, UK

and

Helen Ford

RGN, BSc (Hons), MSc, PGCE (HE)

Senior Lecturer
Department of Nursing, Midwifery and Healthcare
Faculty of Health and Life Sciences
Coventry University, UK

WILEY-BLACKWELL

A John Wiley & Sons, Ltd., Publication

This edition first published 2011
© 2011 Blackwell Publishing Ltd

Blackwell Publishing was acquired by John Wiley & Sons in February 2007. Blackwell's publishing program has been merged with Wiley's global Scientific, Technical and Medical business to form Wiley-Blackwell.

Registered office: John Wiley & Sons Ltd, The Atrium, Southern Gate, Chichester, West Sussex, PO19 8SQ, UK

Editorial offices: 9600 Garsington Road, Oxford, OX4 2DQ, UK
The Atrium, Southern Gate, Chichester, West Sussex, PO19 8SQ, UK
2121 State Avenue, Ames, Iowa 50014-8300, USA

For details of our global editorial offices, for customer services and for information about how to apply for permission to reuse the copyright material in this book please see our website at www.wiley.com/wiley-blackwell.

The right of the author to be identified as the author of this work has been asserted in accordance with the UK Copyright, Designs and Patents Act 1988.

All rights reserved. No part of this publication may be reproduced, stored in a retrieval system, or transmitted, in any form or by any means, electronic, mechanical, photocopying, recording or otherwise, except as permitted by the UK Copyright, Designs and Patents Act 1988, without the prior permission of the publisher.

Designations used by companies to distinguish their products are often claimed as trademarks. All brand names and product names used in this book are trade names, service marks, trademarks or registered trademarks of their respective owners. The publisher is not associated with any product or vendor mentioned in this book. This publication is designed to provide accurate and authoritative information in regard to the subject matter covered. It is sold on the understanding that the publisher is not engaged in rendering professional services. If professional advice or other expert assistance is required, the services of a competent professional should be sought.

Library of Congress Cataloging-in-Publication Data

Long-term conditions : a guide for nurses and healthcare professionals / edited by Sue Randall and Helen Ford.
p. ; cm.
Includes bibliographical references and index.
ISBN 978-1-4443-3249-0 (pbk. : alk. paper)
1. Long-term care of the sick. 2. Chronic diseases–Nursing. I. Randall, Sue, editor. II. Ford, Helen, 1967- editor.
[DNLM: 1. Long-Term Care–methods. 2. Chronic Disease–nursing. 3. Palliative Care–methods. WX 162]
RT120.L64L66 2011
362.16–dc22

2010048240

A catalogue record for this book is available from the British Library.

Set in 9/12.5 pt Interstate Light by Aptara® Inc., New Delhi, India

1 2011

This book is dedicated to my family in recognition of their unwavering support for me, even when my work appears to take priority over my family.

So for my Mum and Dad, Joy and David Gill, my brother and his wife, Steve and Isobel Gill, and my beautiful nieces Sarah and Lauren, thank you.

For Tanya Hughes, whose friendship from the other side of the world keeps me sane, especially when others are asleep.

Last, but certainly not least, a very particular mention is needed for my husband Duncan Randall and my two very special boys, Matthew and Harry, who put up with lot!

Thank you all, so much. It means everything to know you are all there.

Sue Randall

I would like to dedicate this book to my lovely family: Andy, Imogen and Thomas. Thank you for your patience, support and ability to de-stress me by reminding me that there is a whole other world out there!

Thanks are also due to all the people involved in the reading of chapters, for their feedback and comments. Tony Privitera, in particular, was invaluable with his comments for the first draft of Chapter 1.

Both Sue and I are also grateful to the staff of Wiley for their support during the writing and editing of this book. The chapter contributors also deserve a mention, for their diligence in responding to the often-tight deadlines.

Helen Ford

Contents

Contributors

Darren Awang
Darren Awang is Course Director for the MSc in Assistive Technology at the Department of Occupational Therapy, Coventry University. Darren has a strong interest in assistive technology, home adaptations, research methods and applied research. Darren is currently leading a project to develop an online Assistive Technology Learning Tool to assist students and practitioners to gain understanding of the range of assistive technology and its potential to enhance the lives of service users, patients and carers.

Bernie Davies
Bernie Davies is Senior Lecturer in Adult Nursing at Coventry University. She teaches pre- and post-registration students across modules including long-term conditions, evidence-based practice, continence promotion and wound care. She has a particular interest in interprofessional education and is a lead for the online interprofessional learning pathway delivered across health and social care courses at Coventry University and Warwick medical school. She has worked as a sister and then clinical teacher in older adult rehabilitation and in acute medicine.

Helen Ford
Helen Ford is Senior Lecturer at Coventry University, whose predominant responsibility is pre-registration teaching. Helen trained in the West Midlands and worked in clinical practice for 10 years, specialising in medical admissions. The poor nutritional state of many of the patients sparked her interest in patient nutrition, and though nutrition has gained much interest in recent times, she feels that there is scope for more education to help those working with people with long-term conditions adopt a multiprofessional approach.

Jo Galloway
Jo Galloway is Deputy Director of Nursing, Quality and Safety at NHS Warwickshire. Her career spans acute care, commissioning and education, and she has a wealth of experience in managerial, clinical and educational roles in a number of senior posts, both within the NHS and higher education institutions. Her clinical expertise is within rehabilitation and the care of older people. Jo has also co-authored a book on leadership and management in healthcare.

Gay James
Gay James started her nursing career with RGN training at Westminster Hospital, London, followed by experience in general medicine and surgery at Westminster and Kings College Hospital, then Intensive Care course at Guys hospital. Following an MSc in Pain Management, Gay came to realise that the subject of pain is an important priority for patient care, and that learning about it should start in pre-registration education. She hopes that her enthusiasm for improving recognition and appropriate management for pain inspires students to make it a priority for patients.

Jill Main
Jill undertook her nursing training at Edinburgh University and qualified in 1978. She has extensive experience in the fields of both elderly and generalist palliative care. Her academic qualifications include a BSc (Social Science/Nursing) and an MSc (Health Sciences Research). She currently works in South Birmingham Community Health in the Safeguarding Vulnerable Adults team, and also has a remit for end-of-life care in the Trust.

Sue Randall
Sue Randall is Senior Lecturer and Pathway Leader for Long-term Conditions in the Department of Nursing, Midwifery and Health Care at Coventry University, where she teaches across foundation degree, pre-registration, undergraduate and postgraduate nursing. In addition, Sue has an applied research portfolio which includes workforce transformation around the long-term conditions agenda, and evaluations of community matron services. Sue trained at The Middlesex Hospital in London, specialising in orthopaedics and working in elective, trauma and at the supraregional bone tumour unit. From there, she worked as a Health Visitor with a generic caseload of young families and housebound elderly, before establishing the Stop Smoking in Pregnancy Service in South Warwickshire. All of these eclectic experiences have built up a knowledge base which promotes the skills required in current healthcare to support individuals with long-term conditions.

Annette Roebuck
Annette Roebuck is an occupational therapist with experience in a wide range of health and social care settings. Her interest in risk assessment and management was initially sparked when undertaking home visits. The debates that occurred between the multidisciplinary team, clients and family members when attempting to meet clients' wishes underlined the complexity of this issue. Experience in a low secure unit for people with challenging behaviour added a new dimension to her perspectives on risk and empowerment. She now lectures at Coventry University and uses risk management knowledge to empower service users to be members of the module team.

Andrew R Thompson
Dr Andrew R Thompson is Senior Clinical Lecturer and Chartered Clinical & Chartered Health Psychologist. He is employed on the Sheffield NHS/University of Sheffield Clinical Psychology Training Programme as Director of Research Training. In addition, he provides two clinical sessions per week at Rotherham NHS Foundation Trust providing a Clinical Health Psychology service focusing on assisting adjustment to LTCs. He has a long-standing research interest in adaptation to disfigurement.

Robert Tummey
Robert has been working in mental health nursing for over 20 years as both a clinician and an academic. He has worked on hospital wards, in the community setting, and has been a nurse specialist in three separate fields of mental health and a Nurse Consultant. As a psychotherapist, he has worked in both the NHS and the independent sector, providing an integrative approach to counselling and psychotherapy. Publications include *Planning Care in Mental Health Nursing* and *Critical Issues in Mental Health*. Currently, he is Course Director of Mental Health Nursing at Coventry University and in the midst of PhD study.

Andy Turner
Dr Andy Turner is a Senior Research Fellow and the Lead for the Self Management of Long-term Health Conditions research group in the Applied Research Centre in Health & Lifestyle Interventions at Coventry University. He has been evaluating health coaching and self-management programmes

for patients and their carers for over 10 years and has published over 30 self-management papers and book chapters. He is trained in motivational interviewing and psychological coaching and is a personal trainer. He has recently developed the Help to Overcome Problems Effectively (HOPE) health coaching and support programme for people living with long-term health conditions and their carers.

Gillian Ward
Dr Gillian Ward is an occupational therapist and a principal lecturer in assistive technology at Coventry University, lecturing on undergraduate and postgraduate courses. She has a keen interest in the use of assistive technology to support older people and those with LTCs. She also works with the Health Design and Technology Institute at Coventry University to support workforce development needs in relation to assistive technology and provide academic leadership, governance and ethical advice on usability studies of assistive technology products.

Claire Whittle
Claire qualified as an RGN in 1982 at the Queen Elizabeth School of Nursing. After two staff nurse posts, she specialised in Intensive Care Nursing where she became a sister and clinical teacher. Claire lectured in nursing at the University of Birmingham from 1995–2009. For the past 10 years, she has developed a special interest in the development of Integrated Care Pathways, and is working with clinical staff to develop care pathways across a variety of care settings. Claire has been involved with the development and leading the evaluation of the Supportive Care Pathway, a pathway for patients with life-limiting illness with supportive care needs irrespective of diagnosis. Claire is the chairperson for the Midlands Care Pathways network (PACE, Pathways Association of Central England) and a board member of the European Pathways Association. Claire is now at Heart of England NHS Foundation Trust as a Faculty of Education Quality Manager.

Introduction – Rationale and Ethos of the Book

This book is intended to place individuals with a long-term condition (LTC) at the heart of healthcare practice. There is currently considerable discussion around the management of individuals with LTCs. The demographic make-up of society is changing with the proportion of older people growing and living longer. A fifth of the population is over 60 and the over-85s are the fastest growing sector (DH 2008). Currently, 15.4 million people in England report living with an LTC and this is projected to rise to 18 million by 2025 (DH 2008).

Social attitudes are also changing. The Darzi Report (DH 2008) highlights growing expectations of healthcare within the general public. Other policy (DH 2006) recommends changes in the way services are delivered, with patients and service users having more control, as well as closer links between health and social care. Emphasis is now on managing and living with an LTC with 'co-production' of health and care outcomes which are supportive and enabling of care closer to home (DH 2008).

Enabling the workforce to reflect on and improve practice is a key focus of this book. Rather than being disease-focused, it aims to break down key issues and concepts which unify many different LTCs. This will include psychological and social issues that make up a considerable part of living with an LTC. The use of care studies will link the concepts to specific diseases, allowing the reader to build their own knowledge and link theory to practice.

The major difference with this book is a move away from a disease-focused medical model. It aims to consider key elements of living with an LTC based on a partnership approach, to marry the needs of individuals with those of future and current health professionals.

The book is split into 3 sections:

- Section 1: Living with a Long-term Condition
- Section 2: Empowerment
- Section 3: Care management

Within each of the chapters, issues of policy, culture and ethics are intertwined. Learning objectives will assist the reader. Resources and areas of further reading are also outlined for potential exploration. Links to specific LTCs are made through the case studies, where appropriate. These, often moving examples, are followed by points for reflection through which readers can consider their own practice.

Section 1: Living with a Long-term condition

Chapter 1: **Nutrition**: Helen Ford
This chapter considers one of the most fundamental aspects of life, that of nutrition. Although the subject of much current research, nutrition is still a factor that is easily overlooked in clinical practice, perhaps because it can appear to be a complex subject. The chapter by Helen Ford aims to demystify the subject, and demonstrates through the use of case studies how knowledge about nutrition can be incorporated into the practice of caring for individuals with an LTC.

Chapter 2: **Chronic Pain: Living with Chronic Pain:** Gay James
Gay James's comprehensive chapter on the management of pain is written around the central theme that chronic pain is, in itself, an LTC. Starting with a useful examination of the physiology of pain, the chapter continues with the prevalence of chronic pain and strategies for effective assessment of chronic pain, including assessing pain in those with cognitive impairment. Using the WHO pain ladder, appropriate treatment modes are explored.

Chapter 3: **Depression and Long-term Conditions**: Robert Tummey
Robert Tummey's chapter addresses some of the key issues and themes around the acknowledgement, impact and subsequent treatment of depression in individuals living with an LTC. Depression as a cause or consequence of an LTC and the resulting experience are examined. Prevalence of depression, terms and definitions help to promote understanding of depression.

Section 2: Empowerment

Chapter 4: **Adaptation in Long-Term Conditions: The Role of Stigma Particularly in Conditions that Affect Appearance**: Dr Andrew R Thompson
Critical to the way that individuals meet the challenge of an LTC diagnosis is adaptation to a new, often challenging way of life. In Andrew Thompson's chapter, psychosocial impacts are explored and the variation found in individuals of these impacts. The chapter demonstrates how interventions can facilitate adaptation and reduce stigmatisation, with an emphasis on empowerment. Finally, the chapter makes practical suggestions for clinical practice.

Chapter 5: **Self-management in Long-term Conditions**: Sue Randall and Andrew Turner
This chapter by Sue Randall and Andrew Turner considers the move in relationships between healthcare professionals (HCPs) and patients. It defines self-care and self-management and discusses the context of self-management for those individuals living with an LTC. It considers underpinning theories on which models to empower individuals in self-management are based. Through the use of case studies, examples of the effectiveness of self-management as a cornerstone of the management of LTCs are examined.

Chapter 6: **Assistive technology – A Means of Empowerment**: Darren Awang and Dr Gillian Ward
In this exciting chapter, Darren Awang and Gill Ward consider what is meant by the term 'assistive technology' and how this is empowering individuals with LTCs to be partners in care. It also considers the impact of technology on healthcare professional's management of care. It gives consideration to training needs of HCPs, as well as a glimpse at future developments.

Chapter 7: **Risk and empowerment in Long-term Conditions**: Annette Roebuck
Annette Roebuck's chapter explores the challenges for HCPs of managing risk in a meaningful way, which does not prevent individuals with LTCs from living their lives. Empowering individuals with LTCs and the role this plays in the patient/HCP relationship and in managing risk is also examined.

Section 3: Care management

Chapter 8: **Care coordination for Effective Long-term Condition Management**: Sue Randall
The context of the LTC agenda is explored in this chapter. Sue Randall considers care coordination in its broadest sense across many boundaries, and then brings this into focus in the way everyday services are managed to promote effective and quality care for individuals with LTCs by HCPs.

Chapter 9: **Rehabilitation in Long-term Conditions**: Bernie Davies and Jo Galloway
Rehabilitation is no longer solely carried out in wards, and this chapter by Bernie Davies and Jo Galloway brings the subject of rehabilitation up-to-date. Care closer to home is explored, as well as other settings for effective rehabilitation. The factors influencing patient choice are discussed, balanced with the need to manage a diversity of providers. With this in mind, co-ordination of care becomes ever more important, cutting across the boundaries with social care.

Chapter 10: **Palliative care in Long-term Conditions: Pathways to Care**: Claire Whittle and Jill Main
As this chapter by Claire Whittle and Jill Main shows, though palliative care is a concept tied with cancer, it also applies to those dying with an LTC. The principles of symptom control and family care are entirely relevant to LTCs, and the chapter explores various frameworks and models that can be used to assist those whose practice involves caring for the dying. Very often, however, disease trajectories for those with LTCs are not linear, and the chapter also examines when palliative care should start.

Consideration of what constitutes an LTC

In recent times, there has been a move away from the term 'chronic illness' to a more positive term: that of long-term conditions. When undertaking a literature search, it is sensible to use both terms to ensure a comprehensive literature base is uncovered. In the USA, and indeed the World Health Organisation typically use the term 'chronic illness' or 'disease'. However, it can be argued that having a diagnosis of a chronic health problem does not mean ill health as such. LTCs can be seen on a continuum. There are many individuals with hypertension or asthma who, through taking appropriate medication and altering lifestyle where appropriate, are continuing life in their usual way. Of course, both these disease processes carry the risk of extreme consequences: stroke may result from hypertension, whereas a person with asthma suffering a severe attack may require ventilation. Both diseases can result in death.

At the other end of the spectrum, a progressive and aggressive LTC, such as motor neurone disease, can affect an individual's ability to carry out activities of daily living from soon after diagnosis. It is this complexity which makes a patient-centred approach to care so imperative in ensuring that life is of good quality for individuals with an LTC and for their carers. In addition then, to being aware of disease processes, good quality care results from healthcare professionals working together across

boundaries for the good of patients. After all, without patients healthcare professionals (HCPs) are redundant!

It is not unusual for HCPs to feel anxious when they lack knowledge about a disease. However, everyone cannot know everything about all things. The key is partly to know where to find the information required – colleagues, both in your organisation and outside, patients and carers, third-sector organisations, books, internet, etc. – can all be valuable sources.

Equally important is the ability to think outside the box and to think in terms of the skills and knowledge you do have. A patient may be admitted who has advanced Multiple Sclerosis. You may not be familiar with this disease, but have a lot of experience caring for people with stroke. Certain difficulties experienced by both patients will be the same: communication difficulties, swallowing difficulties, mobility difficulties, issues around toileting, and so on. So start with what you know, and seek help to build up the specialist knowledge required for every new situation. We hope that this book will be a useful starting point to empower you to do this.

Sue Randall and Helen Ford
May 2010
The editors are happy to be contacted by email:
s.randall@coventry.ac.uk
h.ford@coventry.ac.uk

Every effort has been made to contact all the copyright-holders for permission to reproduce images. However, in some cases we have been unable to reach copyright holders, despite strenuous efforts. We would be pleased to acknowledge any such diagrams in the first instance.

References

Department of Health (DH) (2006) *Our Health, Our Care, Our Say*. London: The Stationery Office.
DH (2008) *High Quality Care for All (The Darzi Report)*. London: The Stationery Office.

Section 1

Living with a Long-term Condition

Chapter 1
Nutrition

Helen Ford

Learning objectives

After reading this chapter, the reader will have:

- Gained an understanding of how nutrition is a factor both in the cause of LTCs and as a treatment of LTCs
- Developed their understanding of the components of a healthy diet, and be able to demystify dietary advice for patients/clients
- A greater knowledge of obesity, its aetiology, link to LTCs, and current treatment recommendations
- Enhanced their understanding of undernutrition in LTCs, and how this can be identified and treated effectively

Introduction

This chapter explores the importance of good nutrition in both the prevention and management of long-term conditions (LTCs). The impact of poor diet and nutrition on individuals will be discussed, including obesity and, at the other extreme, undernutrition. In particular, the reasons why people with LTCs are at risk of poor nutrition will be examined, including both the effects of hospitalisation and exacerbations of disease. By the end of the chapter, it is hoped that the reader will have a solid foundation of knowledge about nutrition, and that they will be able to use this knowledge in improved assessment and care of their patients.

Nutrition in context

The Department of Health (DH) (2008a) state that 15. 4 million people (almost one in three of those living in England) have an LTC. This statistic includes people across the age continuum, yet of those over 60, the proportion with an LTC increases to three out of five people. As has been identified

Long-term Conditions: A Guide for Nurses and Healthcare Professionals, First Edition. Edited by S. Randall and H. Ford.
© 2011 Blackwell Publishing Ltd. Published 2011 by Blackwell Publishing Ltd.

elsewhere in this book, LTCs do not necessarily occur singly as people may have more than one LTC, and again this incidence rises as age increases. For example, to look at some common conditions:

- In England, 6.7 million people have clinically identified hypertension.
- Diabetes (Types 1 and 2) affects 174, 000 or 6% of the Welsh population.
- 864, 000 people will experience a stroke at some point in their lives across England and Northern Ireland.
- Coronary heart disease affects almost 2 million people in England, from a population of approximately 61 million. This equates to 3.3% of the population, whereas in Scotland this percentage rises to 4.2%.
  Sources: Department of Health 2008b, The Scottish Executive 2003, Welsh Assembly Government 2008, Northern Ireland Executive 2009.

For conditions such as these, diet has been identified as one of the main factors influencing whether someone will develop them or not. Demographic data from the DH suggest that there is wide variation in prevalence of these diseases across the United Kingdom and access to the right kinds of foods to maintain a healthy diet is undoubtedly important. For example, the White Paper 'Towards a Healthier Scotland' (The Scottish Office 1999) stated that Scotland's diet is a major cause of poor health, and that the Scottish diet is traditionally high in fat, salt and sugar, and low in fruit and vegetables. In addition, households that include someone with an LTC are more likely to be low earners, and those on low wages are less likely to be able to afford or have access to healthy food. The World Health Organisation (WHO 2002: 30) in their consultation document 'Diet, Nutrition and the Prevention of Chronic Disease' argue that in fact, events during the life-course of an individual are as important when considering good nutrition as focusing on snapshots in time, and that

> such factors are also being recognized as happening further and further 'upstream' in the chain of events predisposing humans to chronic disease.

However, it must be recognised that some LTCs are not precipitated by diet and other lifestyle factors. For individuals with conditions such as chronic obstructive pulmonary disease (COPD), rheumatoid arthritis (RA) or osteoarthritis, neurological conditions such as epilepsy, motor-neurone disease or multiple sclerosis, or mental health problems such as depression or dementia, poor diet may not have been a factor in the cause of the disease. However, as the reader will see, research into the role of good nutrition and health is showing that interventions to ensure that malnutrition is prevented, detected and managed can positively affect the outcome of a disease, modify symptoms, and reduce morbidity and mortality. This idea, of promoting nutrition to the forefront of a care programme, can be known as 'nutrition as treatment' and it recognises the power of carefully planned nutrition interventions to maintain positive health. However, nutrition does not happen in a vacuum, and the social, cultural, political and economic environment in which a person lives will all affect their eating habits.

How nutrition fits into the management of LTCs

As the number of people with one or more LTCs continues to grow over the next 20 years, the DH (2005) argue that health and social care services will need to focus on improving health outcomes through better detection and prevention of health problems. Promoting the benefits of a healthy lifestyle, including diet, can improve a person's quality of life and allow them to lead as full a life as

they choose rather than becoming isolated and defined solely by their disease. An example of this is hypertension. The Health Survey for England (Office for National Statistics 2005) found that among people with no LTC, approximately 9% had a blood pressure (BP) above 150/ 90. However, this figure rose to 50% for people with one or more LTCs. The DASH (Dietary Approaches to Hypertension) study (Harsha et al. 1999) is a famous study that showed after eight weeks of a diet rich in fruit and vegetables and low fat dairy products, an 11.4 mm Hg drop in systolic BP and a 5.5 mm Hg drop in diastolic BP was observed in hypertensive subjects, compared with those eating a standard American diet. Gaining control of blood pressure alone would reduce the risks of further health problems and may also mean fewer tablets to take in the morning! For the person with an LTC, well-being would be improved as their confidence increased in their ability to manage the disease, rather than the disease managing them, and this could in turn lead to further positive changes in lifestyle.

Promoting health

The DH has identified four levels of care for LTCs (DH 2005). The first level is that of *promoting health*, both in the population as a whole to prevent LTCs from developing in the first place, and for those already with an LTC. For those working in health and social care, supporting people to make healthy choices is as important as other more clinical roles. Good knowledge of what constitutes a healthy diet is important here, as is being able to empower people to manage obesity and stabilise weight. Hydration must be included within this; for example, adequate hydration reduces risk of falls among the elderly (American Geriatrics Society, British Geriatrics Society and American Academy of Orthopaedic Surgeons Panel on Falls Prevention 2001). An example of a visually appealing tool to promote healthy hydration has been produced by the British Nutrition Foundation (2010b) and can be seen in Figure 1.1.

Supported self-care

The second level is *supported self-care* and aims to empower people with LTCs to manage their condition effectively by improving skills and knowledge. The Expert Patients Programme (EPP), for example, is one initiative where individuals are trained by others with an LTC in how to best help themselves to cope with their condition. How to improve diet and maintain optimum health is one of the possible training sessions available in the EPP.

Disease management

The third level of care delivery is that of *disease management*. Here, proactive disease management to diagnose problems and work actively with patients who have a single LTC or range of problems can make a difference to their health and well-being. An example would be a patient with Type 1 diabetes mellitus, who has a designated contact such as a Diabetes Nurse Specialist to help advise on what to do in the event of illness that might impact upon good glycaemic control.

Case management

Finally, for the most complex cases or patients with high-intensity needs, *case-management* is used. Here, a community matron, for example, works as a single point of contact to look holistically at a person's needs and prevent, where possible, unplanned hospital admissions. As will be seen later in this chapter, prevention of undernutrition for people with high-intensity needs will reduce the downward spiral of decline that can lead to hospitalisation or long-term institutionalisation.

With these thoughts in mind, it is now time to think about what nutrition is.

Section 1

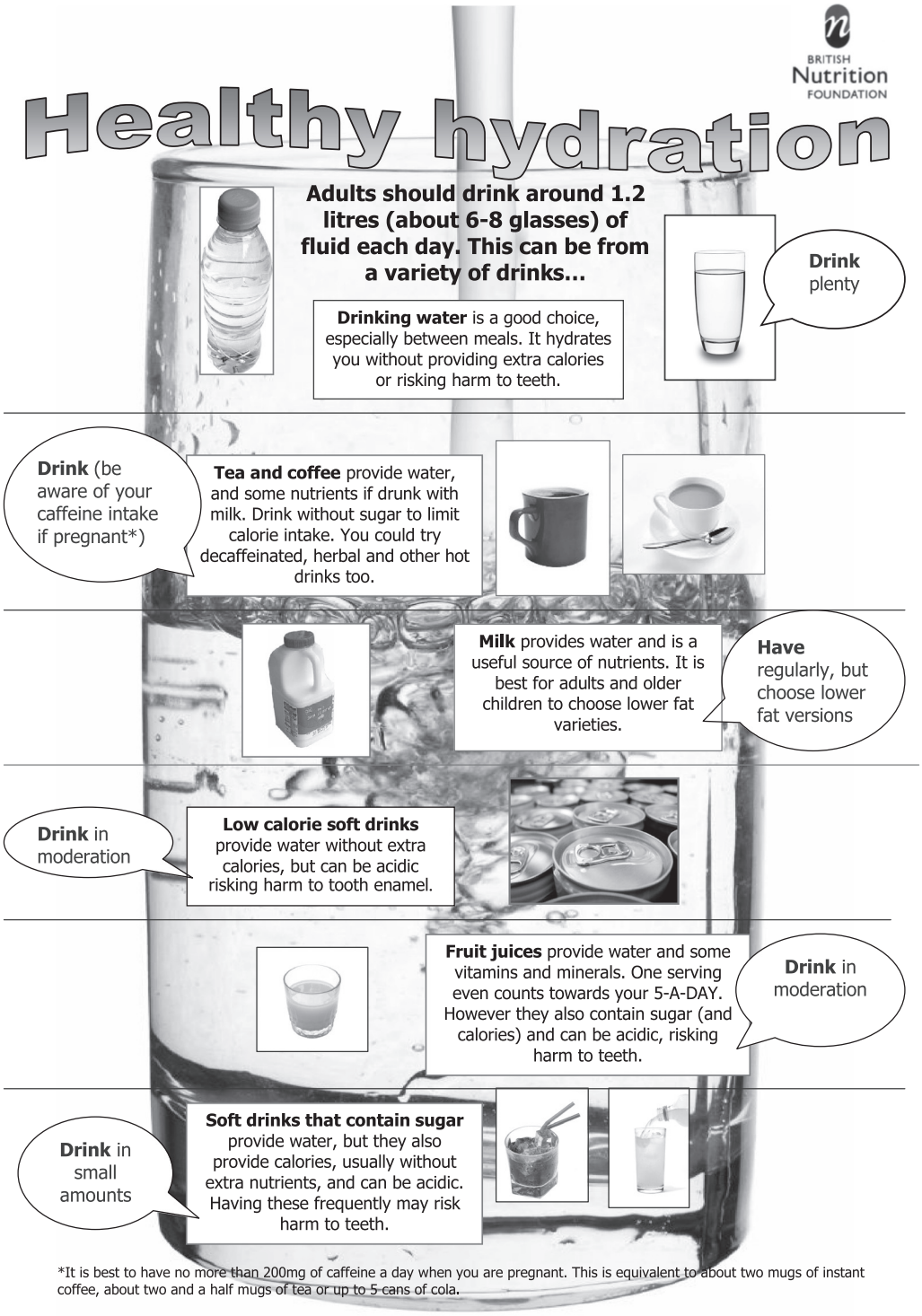

Figure 1.1 Healthy hydration. (British Nutrition Foundation 2010b.)

What is nutrition?

Definitions of nutrition vary, depending on the source. The Wellness Community (2009) is an American non-profit organisation that provides support for people with cancer. They define nutrition as:

> A three-part process that gives the body the nutrients it needs. First, you eat or drink food. Second, the body breaks the food down into nutrients. Third, the nutrients travel through the bloodstream to different parts of the body where they are used as 'fuel' and for many other purposes. To give your body proper nutrition, you have to eat and drink enough of the foods that contain key nutrients.

This definition is useful in that it gives lay people a simplified version of what nutrition is, yet from a biological perspective. It emphasises the physiological processes that enable the body to extract the nutrients it needs from the food or liquid consumed. However, it must be obvious to the reader that nutrition is not just about the acquisition of nutrients. Another definition of nutrition is:

> the study of the relationship between people and their food.
>
> (Barasi 2003: 4)

This definition is somewhat different, as it introduces the notion that food is not simply fuel, but a part of people's everyday lives in the same way that a partner or a child may be. It acknowledges that although food is a necessity, it is also part of a complex web of social and psychological processes, and as such has been the subject of much research by social scientists. An illustrative example of this can be found in the Food Standard Agency's (FSA) (2002) survey on 'Food Fundamentals'. The FSA interviewed adults from different social groups in order to understand their attitudes and approaches towards food, including food trends and food scares. They found that the people interviewed could be divided into the following three broad groups:

- *Enthusiasts:* These were a minority of the sample who were deeply involved with food, who enjoyed all aspects of its preparation and consumption, and were confident they knew what was good or bad.
- *Functional eaters:* The other minority, at the opposite end of the spectrum from the enthusiasts, who looked upon food as fuel, and were mainly concerned with value and cost.
- *Consumers:* The largest group, who enjoyed and consumed food and its associated products and media, and were receptive to food fashion and marketing.

Habits and attitudes

The habits of these broad groups of people are just one way of identifying attitudes of people towards their diet. The implications of groupings such as this are that they can contribute to a deeper understanding of the factors that shape food choices, from among the many different choices that can be made. The survey above showed that eating habits differ between age groups: convenience foods were believed to be becoming increasingly popular, particularly in those aged 20–30. The older respondents, however, felt that convenience foods encouraged lazy eating habits, and on occasion criticised their own children for taking grandchildren to fast-food outlets. This type of information is useful because in understanding how people make choices regarding food, healthcare interventions on diet and nutrition can be more closely tailored to the values and needs of the individual. However, the very word 'choices' here may be misleading, as for some people their choice is severely limited by the money or time available to them. The DH (2008a), for example, state that households that contain

someone with an LTC are more likely to have a low income and that this will have a measurable effect on the quality of food purchased and eaten.

In order to effectively engage with people about nutrition, healthcare professionals need to recognise that attitudes about food are fundamental, particularly when exploring strategies for change as in LTC management. Telford et al. (2007) conducted a qualitative study into the meaning of nutrition for people living with a chronic disease. They found that, for those who took part in the study:

- Nutrition is more than eating; it 'nourished the soul'.
- Having an LTC could disrupt family routines as the individual could not bear the thought of eating or food preparation, for example.
- Having an LTC such as diabetes meant constantly having to think about food; eating was not done when hungry, instead it was done for 'blood sugars'.
- Indulging in certain foods (such as chocolate for a person with diabetes) caused the person to feel 'bad', 'irresponsible', and led to feelings of reduced personal effectiveness and self-esteem.

How food is produced, where raw materials come from, where food is obtained, how it is cooked, how it is served and the very purpose of diet can be, in the developed world, a matter of individual preference. By understanding this, it is possible to engage with patients or clients in a meaningful way and enable care that takes these factors into account.

Summary

Gaining adequate nutrition is complex, and is not just about getting enough calories. Attitudes to food can shape how people, including those with LTCs, make food choices.

Basics of nutrition

At a very basic level, nutrition can be seen to form a balance between the requirements of the body and the nutrients necessary to keep it functioning. However, the term 'nutrients' does not provide much information in itself, and so can be further divided into micro- and macro-nutrients. Before reading about nutrients, a read of Case study 1.1 should help illustrate why it is important for health professionals to understand about the basic building blocks of nutrition.

Case study 1.1 Ray

Aby Taylor works in a GP practice as a Practice Nurse. She is responsible for diagnosing and managing diabetes, in partnership with patients. Today, she is seeing a 72-year-old man called Ray, who has been diagnosed with Type 2 diabetes a year ago. As well as this, Ray has hypertension, high blood cholesterol and has a body mass index of 31, making him obese. He has been prescribed a range of medications to treat his conditions but Aby feels that Ray could be supported to take a more active role in his disease management, including that of his diet. By his own admission, Ray has never really taken much interest in food, and as a life-long single man has not needed to cook for himself. Instead, he would and still does eat his main evening

meal at the local pub, along with a few pints of beer. Since his diagnosis, Ray has developed some of the symptoms of complications of diabetes, in particular, a lack of feeling in his toes and legs. This is a result of persistently high blood sugar. Although Ray realises the seriousness of this, he still does not entirely see the need to manage his diet more carefully. He has tried to eat more fruit and vegetables, but finds this hard because he does not like vegetables. Ray enjoys curries and 'meat and two veg' type meals, without the vegetables. Ray has stated that he would rather 'live his life as he wants' as opposed to conforming to someone else's idea of a healthy lifestyle.

Points for reflection

- What impact is Ray's diet having upon his glycaemic control?
- What knowledge does Aby need to have about the role of specific nutrients in Ray's diet?
- What are the good and bad aspects of Ray's diet?
- How can Aby work with Ray to help him have a healthier diet?

Ray's attitude to food is, in part, shaping his attitude to the diabetes. Ray has viewed food as fuel, as a means to an end, rather than something to take a great interest in. Having not had a family, Ray has only had to please himself with regard to what he eats, and views shopping as a chore. Currently, he is aware that he needs to make changes to his diet and think more about 'healthy eating'. However, it is likely that his understanding of what makes a diet healthy is sketchy, and he may lack the practical skills needed to turn knowledge of this into actual meals.

Ray's diet is likely to be too high in saturated fat and salt. Pub meals are often made up by catering companies and reheated in the kitchen so Ray cannot know the nutrition content of his meals. Similarly, ready meals, which Ray may be tempted to eat for ease of use can contain 40% of the recommended daily intake of salt (FSA 2003). High salt intake could worsen Ray's hypertension. His efforts to increase his intake of fruit and vegetables are to be commended; though making a substantial change to an aspect of lifestyle is often better done in small steps. In addition, although he does not need to stop drinking alcohol altogether, a high intake, over the current recommended guidelines, will also be adversely affecting his blood sugar.

Aby may need to go back to basics with Ray, to assess his understanding of diabetes, diet, and the development of secondary complications such as neuropathy. Ray may not clearly understand how these all link to each other. Once Aby has established Ray's level of understanding, she will find it easier to select the correct information to educate Ray. Aby should also establish what Ray's priorities are in relation to his health. If Ray does indeed not wish to alter his diet and lifestyle, although this will be frustrating to Aby, she will need to respect that it is his choice. Making changes to lifestyle does not happen in a linear fashion for most people, and they may not be ready to make a change, or may relapse after having made that change. Aby must not allow herself to become judgemental as this will reduce the trust that Ray has in their partnership.

Macronutrients

These are the broad food groups that most people are familiar with: carbohydrates, fats, and proteins.

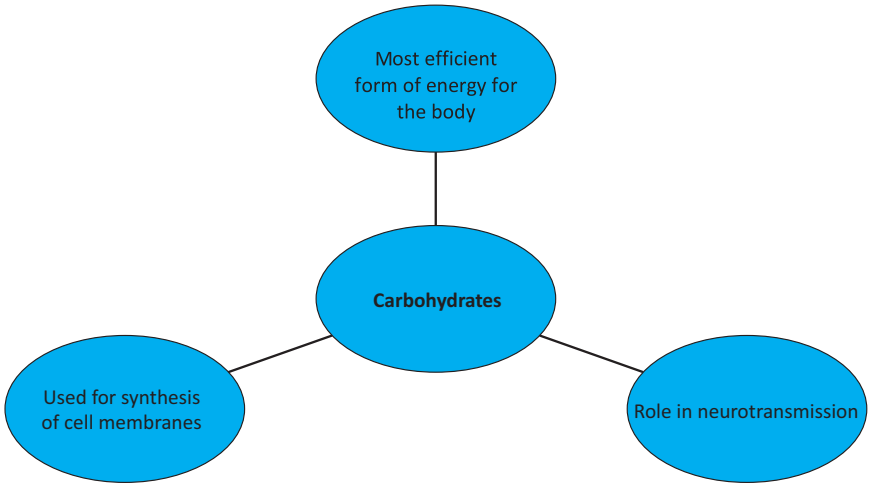

Figure 1.2 Why are carbohydrates necessary?

Carbohydrates

Carbohydrates can be in simple or complex form, yet they are all made up of carbon, hydrogen and oxygen molecules. In their simplest form, carbohydrates are monosaccharides such as glucose, galactose or fructose. Glucose is the most common carbohydrate in the body, and is the primary fuel for organs such as the brain and nervous system. Because of its necessity, glucose is closely controlled within the body by hormones such as insulin and glucagon. Available from sweets, cakes, biscuits, ice creams and honey, intake of refined glucose should be limited; however, plant sources such as fruit and vegetables are encouraged for the other essential components of a healthy diet that they provide. For people with diabetes, intake of fruit and vegetables, and complex carbohydrates is recommended as the cornerstone of an appropriate diet. The reasons why carbohydrates are necessary are illustrated in Figure 1.2.

Disaccharides

Disaccharides are formed when monosaccharides pair up into sucrose, galactose and lactose. Lactose is milk sugar, and apart from milk, it is also present in any food containing milk powder such as some breakfast cereals, chocolate, instant mashed potato and creamed soups. Sucrose is what most people will recognise as sugar, the white crystalline form of which has been the subject of much discussion for its 'bad' properties. The idea that sugar is bad for health originated from thoughts that it provides no nutrition apart from energy, i.e. 'empty calories'. People whose diet is high in sugary foods may consume many calories but will not gain much else nutritionally. However, this statement assumes that sugar is eaten in isolation from the rest of diet, yet studies have shown that where overall energy intake is high, a high intake of sugar may not lead to poor intake of other nutrients (Food and Agriculture Organisation of the United Nations (FAO) 1998). The problem arises for those whose overall energy intake is not so high, so overconsumption of sugar may well lead to imbalance and poor intake of other nutrients. However, the FAO (1998) state that there appears to be no direct link between consumption of sucrose and the development of heart disease. Current advice on sugar consumption favours more complex carbohydrates because of the stability they bring to blood sugar levels, but simple sugars such as sucrose are not necessarily banned, even for people with diabetes.