

HANDBOOK of PALLIATIVE CARE

THIRD EDITION

EDITED BY

CHRISTINA FAULL, SHARON de CAESTECKER, ALEX NICHOLSON & FRASER BLACK



Contents

$\overline{}$,
U	V	C	ı

Dedication

<u>Title Page</u>

Copyright

List of Contributors

Foreword

Preface to the Third Edition

<u>Acknowledgements</u>

Acknowledgement: Cover illustration

List of Abbreviations

<u>Chapter 1: The Context and Principles</u> <u>of Palliative Care</u>

Introduction

What are hospice, palliative care, and end-of-life care?

Issues in palliative care worldwide

Enabling people to be at home
The principles of palliative care
Attaining quality in palliative care
References

<u>Chapter 2: Palliative Care in the Community</u>

Introduction

Palliative care and the general practitioner

Training in palliative care for GPs

District nurses

Community matrons and case mangers

Specialist palliative care services in the

<u>community</u>

Palliative care and the primary care team

Gold standards framework for palliative care

Gold standards framework and the

multidisciplinary team

Palliative and end-of-life care in care homes or residential facilities

Out-of-hours palliative care in the community in the United Kingdom

The future: planning and commissioning future palliative care

Conclusion

<u>References</u>

<u>Chapter 3: Public and Patient Involvement in Palliative Care</u>

Introduction

Part 1: Examples from end-of-life care

Part 2: Why public and patient involvement?

Discussion

Conclusions

References

<u>Chapter 4: Palliative Care: Choice, Equality, and Diversity</u>

Introduction

The environment that breeds inequalities

The current context of care: the model in the

United Kingdom

<u>Understanding inequalities</u>

International dimensions and global disparities

Conclusions: Building choice, equality, diversity,

and responsiveness into comprehensive

supportive and palliative care service

References

Chapter 5: Ethical Issues in Palliative Care

Introduction

Ethics in the context of palliative care

Principles of ethical decision making

Ethical issues in practice

Summary

Legal references and standard abbreviations

References

Useful resources

<u>Chapter 6: Communication Skills in</u> <u>Palliative Care</u>

Introduction

Barriers to effective communication

Facilitative skills

Structuring an assessment

Strategies for specific challenging scenarios

<u>Future care planning: initiating end-of-life care discussions (see also Chapter 8, Advance Care Planning)</u>

Dealing with denial or unrealistic expectations

When language is not shared

Conclusion

References

<u>Chapter 7: Adapting to Death, Dying, and</u> Bereavement

Introduction

Fear of death in society

Holistic needs assessment and identification of emotional distress

Personal spirituality

Adapting to the stark reality of dying

Adapting to bereavement

Summary

<u>References</u>

Chapter 8: Advance Care Planning

Introduction

<u>Termino</u>	loav	and c	defini	tions
ICITITIO	<u>lugy</u>	una c		CIOIIS

The rationale and evidence for ACP

Content of an ACP discussion

<u>Undertaking ACP discussions</u>

Recording the advance care plan

<u>Appointing health-care proxies</u>

What to do when individuals lack capacity for discussions

"Do not resuscitate" discussions

Concerns with ACP

Conclusions

References

Chapter 9: Pain and Its Management

Introduction

The problem of pain in palliative care

<u>Definition of pain and the concept of "total pain"</u>

<u>Terminology</u>

The biology of pain: neuroanatomy and

neurophysiology of nociception and analgesia

Pain types and syndromes

Spiritual and cultural aspects of pain

Assessment of pain

Management of pain

Nondrug interventions

Conclusion

References

Further reading

<u>Chapter 10: The Management of</u> <u>Gastrointestinal Symptoms and Advanced</u> <u>Liver Disease</u>

Introduction

Cachexia, anorexia, and nutrition

Mouth care

Oesophageal problems

Nausea and vomiting

Malignant bowel obstruction

<u>Hiccup</u>

Endoluminal stents

Liver disease

Constipation

Rectal problems of advanced cancer

Stoma care

References

Further reading

<u>Chapter 11: The Management of</u> <u>Respiratory Symptoms and Advanced</u> COPD

Dyspnoea introduction

Dyspnoea pathophysiology

Dyspnoea aetiology

<u>Dyspnoea assessment</u>

Management of dyspnoea

Cough in palliative care

Assessment of cough

Management of cough
Suggested approach to cough
Pleural effusions in palliative care
<u>Haemoptysis</u>
Approach to advanced chronic obstructive

References

pulmonary disease

<u>Chapter 12: Managing Complications of Cancer</u>

Introduction

Spinal cord compression

Superior vena cava obstruction (SVCO)

Bone metastases

Pathological fracture

Brain metastases

<u>Surgical and interventional management of other</u> <u>sites of metastatic disease</u>

<u>Hypercalcaemia</u>

Obstructive nephropathy

<u>Haemorrhage</u>

<u>Itch</u>

Fever and sweating

Side effects of palliative oncology treatments

<u>Lymphoedema</u>

<u>Airway patency and care of the patient with a tracheostomy or laryngectomy</u>

<u>References</u>

<u>Chapter 13: Palliative Care for People</u> <u>with Progressive Neurological Disorders</u>

Introduction

Background

Symptom management

Holistic care for patients with neurological

conditions

End-of-life care

Conclusions

Supportive organisations in the United Kingdom

References

<u>Chapter 14: Palliative Care for People with</u> HIV Infection and AIDS

Introduction

Global epidemiology

HIV and AIDS in the United Kingdom

HIV and AIDS in the Americas

What exactly is palliative care in the context of HIV/AIDS?

Gold standards in palliative care

A new paradigm?

Issues relating to palliative care

Management of common physical symptoms

Issues relating to medication and HIV/AIDS in

palliative care

The end of life

Conclusion

References

Further reading

<u>Appendix A</u>

<u>Precautionary measures at home [12]</u>

Chapter 15: Palliative Care for Children

Introduction

What kinds of children receive palliative care? Is it just children with cancer?

When is the right time for the clinician to consider palliative care for a child?

<u>Does palliative care in children allow "curative"</u> <u>treatments to be continued?</u>

What symptoms are children likely to have?

<u>How do I deal with developmental differences in assessing symptoms?</u>

Are there any tools to help with symptom assessment?

General principles for symptom management in children

Symptom patterns

Notes about some specific symptoms

What medications can I use in children and what doses?

How do I make a reliable prognostication for a child?

Does the primary care provider have a role in caring for children with complex conditions?
What is the best way to work with families of children in palliative care?

How do I advise parents to talk to their children about the illness?

Should families try to continue their routines, or is it better to focus on the ill child?

<u>Is it helpful to tell siblings everything that is happening?</u>

The final stages

The bereaved family

What kinds of professionals provide PPC?

Where is PPC provided (and what difference does

it make)?

Conclusions

<u>References</u>

<u>Chapter 16: Palliative Care for Adolescents</u> <u>and Young Adults</u>

Introduction

The challenge of providing palliative care for young people

The psychology of adolescence and young adulthood

From health to illness

Quality of life

Toward the end of life

Conclusions

References

<u>Chapter 17: Palliative Care for People with</u> <u>Advanced Dementia</u>

100					1.0	•	
ın	T	rn	a	11	ct	\mathbf{n}	n
	ı		u	u	CL	ı	

Types of dementia

Epidemiology

How is palliative care in advanced dementia

different?

Communication issues

Advance care planning

Caring for the carers

Spirituality in dementia

Common physical symptoms in people with

advanced dementia

<u>Terminal care</u>

<u>Admiral nurses</u>

Conclusions

<u>References</u>

Further reading

Useful resources

<u>Chapter 18: Palliative Care in Advanced</u> Heart Disease

Introduction

Heart failure

Prognosis and prognostic models

<u>Interventional aspects of care</u>

Barriers/challenges in extending palliative care to

patients with HF

Palliative care delivery in HF

Symptom management

<u>Dyspnoea</u>

	•
בע	In
Γа	

<u>Fatigue</u>

Anaemia

Oedema/ascites

Psychological/psychosocial

Discontinuing medical therapies

End-of-life care

Conclusion

References

<u>Chapter 19: Palliative Care in Advanced</u> <u>Renal Disease</u>

Introduction

ESRD management

Conservative management

Renal replacement therapy

Symptom management in ESRD

Pain

End of life

Conclusions

References

<u>Chapter 20: Pressure Ulcer Care and the Management of Malignant Wounds</u>

Introduction

Pressure ulcers

Malignant wounds

Conclusion

<u>References</u>

Further reading

Chapter 21: Terminal Care and Dying

Introduction

Helping people to achieve the preferred place for their death

When is a patient terminally ill?

How to assess the needs of a terminally ill patient

Clinical care at the end of life

Therapeutics at the end of life

Special needs of family and lay carers during the

last days of life

Care after death

Conclusions

References

Appendices1

<u>Appendix 1: Management of Pain with</u> <u>Fentanyl Transdermal Patches at End of</u> Life

<u>Appendix 2: Management of Pain at the</u> End of Life

<u>Appendix 3: Management of</u>
<u>Breathlessness at the End of Life</u>

<u>Appendix 4: Management of Nausea and Vomiting at the End of Life</u>

<u>Appendix 5: Management of Respiratory</u> <u>Secretions at the End of Life</u>

<u>Appendix 6: Management of Restlessness</u> <u>and Agitation/Delirium at the End of Life</u>

<u>Appendix 7: Management Diabetes in the Last Days of Life: A Pragmatic Approach2</u>

<u>Appendix 8: Management of Bleeding at the End of Life</u>

<u>Chapter 22: The Syringe Driver and Medicines Management in Palliative Care</u>

Introduction

Pharmacist in palliative care: a key team member

Use of drugs beyond licence

Medication compliance aids

Use of the "syringe driver" for continuous

infusion in palliative care

Obtaining the drugs for the palliative care patient

-seamless care at the

hospital/hospice/community interface

Prescribing and dispensing of controlled drugs

Unwanted medicines or disposal of CDs after a

death at home

<u>Pharmacy and palliative care: the future</u> <u>References</u> Further reading

<u>Chapter 23: Complementary Approaches</u> <u>to Palliative Cancer Care</u>

Introduction

<u>Similarities between complementary therapies</u> <u>and holistic palliative care</u>

<u>Acupuncture</u>

Dietary interventions

<u>Healing</u>

Herbalism

Homoeopathy

Massage, aromatherapy, and reflexology

Mind-body techniques: hypnosis, meditation,

relaxation, and visualisation

Potential problems with CT approaches in

palliative care settings

Supervision and responsibility

Interprofessional issues

Conclusions

References

Further reading

Chapter 24: Spirituality in Palliative Care

Introduction

Spirituality and the need for spiritual care Who provides the spiritual care?

<u>Impact of providing spiritual care on members of the professional care team</u>

<u>Strategies for addressing the spiritual aspect of palliative care</u>

Spirituality and liminal time

<u>Teamwork</u>

Conclusion

References

Further reading

<u>Index</u>

Yvonne Carter has been very much in our minds throughout the preparation of the third edition of the *Handbook of Palliative Care*. Sadly, she was not part of the team on this occasion. After many years living with cancer, she died in 2009 but her voice has been heard loudly by us, giving encouragement and direction throughout the process. We dedicate this edition to her.

Handbook of Palliative Care

EDITED BY

Christina Faull BMedSci, MBBS, MD, FRCP, PGCert Med Ed, Dip Clin Hypnosis

University Hospitals of Leicester and LOROS, The Leicestershire and Rutland Hospice, Leicester, UK

Sharon de Caestecker RN, BN, MA

LOROS, The Leicestershire and Rutland Hospice, Leicester, UK

Alex Nicholson MBBS, FRCP

South Tees Hospitals NHS Foundation Trust, Middlesbrough, UK

Fraser Black MD, CCFP, FCFP

International Network for Cancer Treatment and Research (Belgium/Canada); Victoria Hospice and InspireHealth, Victoria, Canada

3rd edition



Copyright © 2012 by John Wiley & Sons, Inc. All rights reserved

Published by John Wiley & Sons, Inc., Hoboken, New Jersey
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,
scanning, or otherwise, except as permitted under Section
107 or 108 of the 1976 United States Copyright Act, without
either the prior written permission of the Publisher, or
authorization through payment of the appropriate per-copy
fee to the Copyright Clearance Center, Inc., 222 Rosewood
Drive, Danvers, MA 01923, (978) 750-8400, fax (978) 7504470, or on the web at www.copyright.com. Requests to the
Publisher for permission should be addressed to the
Permissions Department, John Wiley & Sons, Inc., 111 River
Street, Hoboken, NJ 07030, (201) 748-6011, fax (201) 7486008, or online at http://www.wiley.com/go/permission.

Limit of Liability/Disclaimer of Warranty: While the publisher and author have used their best efforts in preparing this book, they make no representations or warranties with respect to the accuracy or completeness of the contents of this book and specifically disclaim any implied warranties of merchantability or fitness for a particular purpose. No warranty may be created or extended by sales representatives or written sales materials. The advice and strategies contained herein may not be suitable for your situation. You should consult with a professional where appropriate. Neither the publisher nor author shall be liable for any loss of profit or any other commercial damages, including but not limited to special, incidental, consequential, or other damages.

For general information on our other products and services or for technical support, please contact our Customer Care Department within the United States at (800) 762-2974,

outside the United States at (317) 572-3993 or fax (317) 572-4002.

Wiley also publishes its books in a variety of electronic formats. Some content that appears in print may not be available in electronic formats. For more information about Wiley products, visit our web site at www.wiley.com.

Library of Congress Cataloging-in-Publication Data:

Handbook of palliative care / edited by Christina Faull ... [et al.]. – 3rd ed.

p.; cm.

Includes bibliographical references and index. ISBN 978-1-118-06559-4 (pbk. : alk. paper)
I. Faull. Christina.

[DNLM: 1. Palliative Care-Handbooks. WB 39] 616'.029-dc23 2012014815

Cover Image: © The Map Foundation Cover Design: Michael Rutkowski

List of Contributors

Debbie Allanson, RGN, HND

Lymphoedema Clinical Nurse Specialist The Queen's Centre for Oncology and Haematology Hull, UK

Megory Anderson, MA

Director
Sacred Dying Foundation
San Francisco, USA

Rachael Barton, MA MSc DM MRCP FRCR

Consultant Clinical Oncologist and Honorary Senior Lecturer The Queen's Centre for Oncology and Haematology Hull, UK

Fraser Black, MD, CCFP, FCFP

Medical Director and Palliative Care Physician, Victoria Hospice, Canada InspireHealth, Integrative Cancer Center, Victoria, Canada

Clinical Professor, University of British Columbia, Canada International Network for Cancer Treatment and Research (Belgium/Canada)

Deb Braithwaite, MD, CCFP, FCFP

Community Lead and Palliative Care Physician Victoria Hospice Victoria, Canada

Camara van Breemen, MN, CHPCN(c)

Nurse Practitioner (F)

Canuck Place Children's Hospice, Vancouver, Canada

Sharon de Caestecker RN, BN, MA

Director of Education and Training LOROS, The Leicestershire and Rutland Hospice Leicester, UK

Rodger Charlton, MD, FRCGP

Associate Clinical Professor, Division of Primary Care, Nottingham Medical School Honorary Professor College of Medicine Swansea University Swansea, UK

Andrew Chilton, MBBS, FRCP

Consultant and Honorary Senior Lecturer Gastroenterologist and Hepatologist Kettering General Hospital Foundation Trust Kettering, UK

Monica Compton, BS, AAS

Nutrition Team Dietitian and Lead Dietetic Prescribing Advisor Kettering General Hospital NHS Foundation Trust Kettering, UK

Rachael E. Dixon, MBBS, BSc, MRCP

Consultant in Palliative Medicine Dove House Hospice

Joanna Dunn, MBBS, MRCP, MA

Specialist Registrar in Palliative Medicine UCLH, Camden and Islington Palliative Care Team London, UK

Jacqueline Edwards, RGN, RSCN, MSc, BSc (Hons)

Head Nurse, Children, Quality and Governance Heart of England NHS Foundation Trust Bordesley Green East Birmingham, UK

Christina Faull, BMedSci, MBBS, MD, FRCP, PGCert Med Ed, Dip Clin Hypnosis

Consultant in Palliative Medicine
University Hospitals of Leicester and LOROS
The Leicestershire and Rutland Hospice
Leicester, UK

Liz Grant, PhD

Deputy Director Global Health Academy University of Edinburgh Edinburgh, UK

Jo Griffiths, MBChB, MRCPCH, Dip Pall Med (Paeds)

Consultant in Paediatric Palliative Medicine & Community Child Health Abertawe Bro Morgannwg Health Board, Swansea, Wales, UK

Christine Hirsch, BPharm, PhD

Lecturer in Clinical Pharmacy Medical School

University of Birmingham, Birmingham, UK

Christine Jones, MD, CCFP, FCFP

Palliative Medicine Physician Victoria Hospice Society Vancouver Island Health Authority Victoria, Canada

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

Royal College of Nursing Chair of Nursing Research School of Nursing & Midwifery Studies Cardiff University Wales, UK

Victoria Lidstone, BM, FRCP

Consultant in Palliative Medicine & All Wales Clinical Lead for transition in Palliative Care Department of Paediatric Palliative Care University Hospital of Wales Cardiff, UK

Ryan Liebscher, MD, CCFP

Palliative Care Physician Victoria Hospice Victoria, Canada

Maria McKenna, MBBS, MRCP

Newcastle upon Tyne Hospitals NHS Foundation Trust, UK

Daniel Munday, MBBS, FFARCSI, DRCOG, MRCGP, Dip Pall Med, PhD, FRCP

Associate Clinical Professor/Honorary Consultant in Palliative Medicine

Division of Health Sciences, Warwick Medical School

Alex Nicholson, MBBS, FRCP

Consultant in Palliative Medicine, South Tees Hospitals NHS Foundation Trust, Visiting Fellow, University of Teesside School of Health and Social Care, Middlesbrough, UK

David Oliver, BSc, FRCP, FRCGP

Consultant in Palliative Medicine
Wisdom Hospice
Rochester, UK
And
Honorary Reader
Centre for Professional Practice
University of Kent
Kent, UK

Wendy Prentice, MBBS, FRCP, MA

Consultant/Honorary Senior Lecturer in Palliative Medicine King's College Hospital NHS Foundation Trust Cicely Saunders Institute London, UK

Aziz Sheikh, BSc, MBBS, MSc, MD, DRCOG, DCH, FRCGP, FRCP

Professor of Primary Care Research & Development Director of Research Centre for Population Health Sciences University of Edinburgh Edinburgh, UK

Harold Siden, MD, MHSc, FRCPC

Medical Director

Canuck Place Children's Hospice Clinical Associate Professor, Pediatrics University of British Columbia Vancover, Canada

Surinder Singh, BM, MSc, FRCGP

Senior Clinical Lecturer in General Practice Research Department of Primary Care & Population Health UCL Medical School London, UK

Neil Small, BSc (Econ), MSW, Phd.

Professor of Health Research School of Health Studies University of Bradford Bradford, UK

Sue Taplin, BA (Joint Hons), MA/PgDipSw, DSW

Education Facilitator, LOROS The Leicestershire and Rutland Hospice Leicester, UK

Nick Theobald, MA, MSc, MBBS

Clinical Lecturer and Associate Specialist St Stephen's Centre Chelsea and Westminster Hospital London, UK

Elizabeth Thompson, DMOxon, MBBS, MRCP, FFHom

Lead Clinician/Consultant Homeopathic Physician and Honorary Senior Lecturer in Palliative Medicine University Hospitals Bristol NHS Foundation Trust Bristol Homeopathic Hospital Bristol, UK

Mary Walding, RGN, BSc (Hons), PGDip

Clinical Nurse Specialist Palliative Care Katharine House Hospice Banbury, UK

Richard K.M. Wong, MA, MD, FRCP

Consultant Geriatrician University Hospital of Leicester NHS Trust Leicester, UK

Catherine Zollman, BA(Oxon), MBBS, MRCP, MRCGP

GP

Bristol and Lead Doctor Penny Brohn Cancer Care Bristol, UK

Foreword

Every minute over 100 people die in the world but far too many people still do not get the palliative and end-of-life care they need or want. Even patients in countries with welldeveloped health-care systems such as Europe, Australasia, and North America, who could benefit from the full range of palliative care support and services, never have that opportunity. The consequence is that many die with the distress of uncontrolled symptoms and with relatives and carers who are unsupportive. A difficult time may be made worse because no one has established the wishes of the patient, and they die in a place they would not have chosen and are perhaps subject to inappropriate and futile interventions, such as resuscitation, that they would have declined. Furthermore, it is still unfortunately true that access to palliative care services varies according to age, diagnosis, gender, and geography, and the basic levels of palliative care that are available are of inconsistent quality. The time has come to change this and to change it for good.

My vision is for a "good death" to be the norm. We only get one chance to get it right for people living in the late stages of incurable illness and those who are dying. I believe the *Handbook of Palliative Care* will undoubtedly contribute to achieving this vision by providing evidence-based knowledge for doctors and nurses, and for other members of the multiprofessional team. This new edition is highly impressive and should be required reading for all those involved in delivering palliative care at any level wherever they work in the world. As a practicing general practitioner, I know on a daily basis how a clinician can be faced with complex clinical and ethical dilemmas in patient management. I would find a resource like this book very

reassuring, providing as it does a wide range of trusted knowledge, experience, and expertise.

An ageing population with complex health and social care needs requires a new caring approach and a new deal for the dying. All health-care systems need to effect a change in clinical practice to recognise the dying patient earlier and improve access for these patients to the palliative care and hospice approach—for example, through use of supportive and palliative care registers—particularly for patients with conditions other than cancer. The development of better generalists is a must, as is implementing comprehensive evidence-based guidelines for palliative care. Key to grasping this opportunity is development of the workforce.

And we need to achieve fundamental changes in public professional attitudes. A society that is with talking comfortable about death. dvina. bereavement is much needed. I am therefore delighted that the handbook includes a chapter on communication skills. I also welcome the new chapter on spirituality in this edition. Spirituality is often the missing piece in palliative care plans, even though meeting the individual spiritual needs of a patient is an important part of that person's journey at the end of life.

In 2008, readers of the British Medical Journal voted "palliative care beyond cancer" as the area of health care in which doctors could make the most improvement. This is an outstanding book that is to be thoroughly commended for its broad range of clinical issues and particularly for its focus on noncancer palliative care. All clinicians will recognise that the noncancer patient presents challenges when we are trying to determine the starting point for the last few months of life, but this is critical if we are to identify those patients who need palliative attention and for whom we should be starting advance care planning discussions. I am glad to see practical guidance on this area of practice.