



OXFORD

# **Patient participation in palliative care**

A voice for the voiceless

Edited by

Barbara Monroe

David Oliviere

# Patient Participation In Palliative Care A Voice For The Voiceless

**Peter Speck**



## **Patient Participation In Palliative Care A Voice For The Voiceless:**

**Patient Participation in Palliative Care** Barbara Monroe, David Oliviere, 2003 Patient participation and user involvement are central to current thinking about the effective delivery of desired healthcare outcomes This book addresses key aspects in the provision of patient centred palliative care and tracks significant developments in user involvement

**Patient Participation in Palliative Care** Barbara Monroe, David Oliviere, 2003 Patient participation and user involvement are central to current thinking about the effective delivery of desired healthcare outcomes Working with the person who lies behind every patient is core to palliative care A voice can only become significant when it is listened to and acted upon With palliative care increasingly addressing the needs of people with a variety of conditions in a range of settings as well as with advances in research technology and information the challenge to be a voice for the voiceless is greater than ever This book addresses key aspects in the provision of patient centred palliative care and tracks significant developments in user involvement It sets the philosophy within the cultural social and political context of modern healthcare particularly addressing issues of quality standards education and bereavement A key component in the delivery of high quality palliative care is the multi professional team Following a discussion of teamwork five core professions present a critical analysis of their working practices The book concludes with a commentary from a palliative care user and a bereaved carer It is often somewhat glibly asserted that the patient is or should be at the centre of care There have been few attempts to examine how to keep him or her there without professional needs and protocols crowding him or her out This book asks how we listen and why we listen The book focuses on the challenges of how professionals can keep the needs of the patient central in clinical care and how the patient can influence the direction of that care

*The SAGE Handbook of Health Care Ethics* Ruth Chadwick, Henk ten Have, Eric M. Meslin, 2011-01-18 The SAGE Handbook of Health Care Ethics is an influential collection of work by leading scholars on the fundamental and emerging themes which define health care ethics Combining international and interdisciplinary perspectives the Handbook provides a cutting edge account of debates in five key areas health care ethics in an era of globalization beginning and end of life vulnerable populations research ethics and technologies public health and human rights This authoritative Handbook brings together experts with backgrounds in philosophy sociology law public policy and the health professions and reflects the increasing impact of globalisation and the dynamic advances in the fields of bioscience and genetics which keep ethics at the centre of debates about the future direction of healthcare It is an invaluable resource for all students practitioners academics and researchers investigating ethical issues in relation to healthcare

**Loss, Change And Bereavement In Palliative Care** Firth, Pam, Luff, Gill, Oliviere, David, 2004-12-01 This text brings together contemporary thinking on loss and bereavement It draws on international research practice and individual stories from people struggling to understand the meaning of loss including work with bereaved children parents families and adults

**Illuminating the Diversity of Cancer and Palliative Care Education** Lorna Foyle, Janis

Hostad,2018-04-19 Illuminating the Diversity of Cancer and Palliative Care Education examines a myriad of original approaches techniques methods educational strategies and imaginative innovations within this vital field of medicine Its contributors share a range of educational techniques and tactics from Neuro Linguistic Programming to creative teaching strategies for bereavement support allowing readers to reflect on best practice and inventive ways of working which can be used or adapted to suit This book is an ideal companion to its sister volumes Innovations in Cancer and Palliative Care Education and Delivering Cancer and Palliative Care Education

**Teamwork in Palliative Care** Peter Speck,2006-09-14

Teamwork is a complex but essential component of palliative care The needs of people diagnosed with life threatening disease will vary greatly over time and it is rarely possible for just one professional to be able to provide adequate care In order to ensure an holistic approach the whole multi disciplinary team must be involved Inevitable questions arise from such an approach and this book seeks to address these How does a team come into being What different formats are there How might the patient contribute to the effectiveness of their care and the way in which the team operates What are the difficulties and frustrations encountered in developing and maintaining such teams What models of working and styles of leadership have developed How are power and authority handled within the team setting The importance of team building training support attention to group process and stress management to protect the mental health of the team are explored The ethical issues inherent in palliative care such as consent autonomy confidentiality decision making within teams and the legal implications of such are also discussed The book concludes with one important question do we know if teams are the most effective way of providing care This book addresses key issues surrounding the role of the team in palliative care and is an essential guide to reappraising the importance of collaborative teamwork and enhancing understanding of existing team structures

**Communication as Comfort** Sandra L. Ragan,Elaine M. Wittenberg-Lyles,Joy Goldsmith,Sandra Sanchez Reilly,2008-05-15 This exceptional work explores the complexities of communication at one of the most critical stages of the life experience during advanced serious illness and at the end of life Challenging the predominantly biomedical model that informs much communication between seriously ill and or dying patients and their physicians caregivers and families Sandra L Ragan Elaine M Wittenberg Lyles Joy Goldsmith and Sandra Sanchez Reilly pose palliative care medical care designed to comfort rather than to cure patients as an antidote to the experience of most Americans at the most vulnerable juncture of their lives With an author team comprised of three health communication scholars and one physician certified in geriatrics and palliative medicine this volume integrates the medical literature on palliative care with that of health communication researchers who advocate a biopsychosocial approach to health care Applying communication theories and insights to illuminate problems and to explain their complexities the authors advocate a patient centered approach to care that recognizes and seeks to lessen patients suffering and the many types of pain they may experience physical psychological social and spiritual during life threatening illness

*Palliative Care Nursing* Marianne Matzo,Marianne L. Matzo,Deborah

Witt Sherman, 2018-06-28 This 5th edition is an important achievement it is a symbol of commitment to the field of palliative nursing where we have been and where we are going Betty Rolling Ferrell PhD MA FAAN FPCN CHPN From the Foreword The aging population has only grown since the first edition of this comprehensive and seminal publication nearly 20 years ago Based on the need to humanize rather than medicalize the illness experience for patients this text delves into palliative care beyond the specific diseases affecting the patient Instead content focuses on the whole person and family Palliative patients struggle with chronic debilitating and painful conditions and grapple with the fact that life as they knew it has already passed away Families and friends reciprocally suffer not knowing how to help and therefore become the secondary victims of the disease This is not the challenge of a lone nurse or a single physician therapist or social worker Rather palliative and hospice care requires the expertise and unique roles of an interprofessional team to help the patient and family strengthen their resilience continue to find meaning and purpose in life and cure what can be cured Palliative Care Nursing Fifth Edition delivers advanced empirical aesthetic ethical and personal knowledge This new edition brings an increased focus on outcomes benchmarking progress and goals of care It expounds upon the importance of the cross disciplinary collaboration introduced in the previous edition Every chapter in Sections I II and III includes content written by a non nursing member of the interprofessional team Based on best evidence and clinical practice guidelines this text presents comprehensive targeted interventions responsive to the needs of palliative and hospice patients and family Each chapter contains compassionate timely appropriate and cost effective care for diverse populations across the illness trajectory Key Features The expanded new edition offers current comprehensive one stop source of highly relevant clinical information on palliative care Life span approach age appropriate nursing considerations e g geriatric pediatric and family Includes disease specific and symptom specific nursing management chapters Promotes a holistic and interdisciplinary approach to palliative care Offers important legal ethical and cultural considerations related to death and dying Case Studies with Case Study Conclusion in each clinical chapter New to The Fifth Edition An expanded chapter on Palliative Care incorporates most up to date scope and standards information on Basic and Advanced HPNA certification self reflection and self care for nurses A chapter on Interprofessional Collaboration Instructor Resources Power points and Test bank **Palliative Care: An**

**Integrated Approach** Jenny Buckley, 2008-07-31 This evidence based text brings together the theory and practice of palliative care It examines at all aspects of palliative care i e psycho social spiritual and physical in a highly practical way The evidence base for cancer care has been developed within the Hospice Movement over the past 50 years and in the main it transfers across to patients dying of diseases other than cancer The book addresses the palliative needs of any patient with any disease in any care setting which gives it a generic approach This is in line with current government directives Contributions to care and treatment are considered in a multidisciplinary and complementary way *Enhancing Cancer Care* Jennifer Barraclough, 2007-09-06 A practical evidence based guide to complementary cancer therapies with an emphasis

on enhancing practice that is using the therapies alongside conventional medicine rather than as alternatives to it

**Palliative Care, Social Work, and Service Users** Peter Beresford, Lesley Adshead, Suzy Croft, 2007 This unique book provides a rare look at social work and palliative care from the perspective of service users Drawing on new original research the authors examine service users experiences tracking their journeys through it exploring the care they receive and the effects of culture and difference through their first hand comments and ideas

**Creative Engagement in Palliative Care** Lucinda Jarrett, Sunderarajan Jayaraman, 2017-11-22 This book offers an extensive range of ideas and practical developing service users creativity including songmaking drama dance creative writing music video and visual arts It promotes innovation and encourages a fresh and enthusiastic approach to care that will appeal to anyone with a love of creative arts as a means of expression The wide ranging approach encompasses many different voices from patients artists and healthcare professionals Creative Engagement in Palliative Care is highly recommended for all palliative health and social care professionals and volunteers including occupational therapists and art and music therapists It is a wonderful resource for health and social care educators teachers and trainers and will be a immense source of inspiration for patients and their families This book is about user involvement It is concerned with sharing knowledge and experience about user involvement in palliative care and making it more real for the future In modern times the importance of end of life care was highlighted by the pioneers of the voluntary hospice movement They emphasised the importance of palliative care being based on an holistic approach that took account of all aspects of people s lives and deaths medical social spiritual and material More recently the work of the independent hospice movement has been complemented by the development and expansion of specialist palliative care in state provision The aim has been to enable people to be able to do it their way with a real sense of control and to be able to communicate their unique words voices and experience This is and will always be a key potential of user involvement Suzy Croft and Peter Beresford in the Preface

**International Perspectives on Public Health and Palliative Care** Libby Sallnow, Suresh Kumar, Allan Kellehear, 2013-07-03 Public health approaches to palliative care have been growing in policy importance and practice acceptance This innovative volume explores the major concepts practice examples and practice guidelines for this new approach The goal of comprehensive care seamless support for patients as they transition between home based care and inpatient services relies on the principles of health promotion and community development both to ensure services are available and importantly appropriate for patients needs In developing contexts where hospitals and hospices may be inaccessible a public health approach provides not only continuity of care but greater access to good end of life care This book provides both a historical and conceptual overview whilst offering practical case examples from affluent and developing contexts in a range of clinical settings Finally it draws together research based guidelines for future practice Essential reading for public health researchers and practitioners with an interest in end of life care and global health as well as those involved in developing palliative care provision International Perspectives on Public Health and

Palliative Care is the first volume to present an overview of theory and practice in this emerging field *Resilience in Palliative Care* Barbara Monroe, David Oliviere, 2007-09-06 The first book of its kind Resilience and Palliative Care Achievement in adversity takes the increasing international literature on resilience and applies it to palliative and end of life care The book offers an overview of all key aspects of palliative care presented through a resilience perspective Why do some patients and families break down while others surmounts the challenges facing them What interventions strengthen individual family and community coping This book aims to facilitate change with people facing the crisis of death dying and bereavement Much of the existing literature has focused on risk problems and vulnerability the emerging concept of resilience focuses on strengths and possibilities The total pain total care approach pioneered by Dame Cicely Saunders and St Christopher's Hospice now needs reinterpreting in the light of changing contexts and challenges The realities of demographic change and resource constrained health and social care environments have generated an increasingly risk focused approach to service delivery A narrowly medicalised approach has inevitable limitations professional care alone will be unable to meet need and demand in the face of ageing populations changing patterns of illness and the need for equity The resilience approach offers a counterbalance that harnesses the strengths of individuals and the communities in which they live and in which most of their dying will take place Resilience thinking emphasises the importance of public health and creates a partnership between patients professionals and community structures seeking to build community capacity and to deliver a preventive health care that will leave future generations less afraid of the dying and bereavement that will confront all of us This book offers insights into how at all levels of planning and delivering palliative care there is the opportunity to maximise coping build an infrastructure for self help and increase the capacity of strengthened teams and organisations

**Cicely Saunders** Dame Cicely M. Saunders, 2006-01-05 A remarkable story of a personal vision and sense of calling this text provides an insight into the establishment of the hospice movement and its development world wide *Palliative Care in Nursing and Healthcare* Michelle Brown, 2015-11-09 This book helps nursing and healthcare students to prepare for the challenges of working with the increasing number of patients requiring palliative care so that they can work in partnership with patients and their carers providing care that is compassionate practical and backed up by the latest evidence Delivering palliative care can be emotionally challenging and the book focuses on supporting healthcare staff allowing them to provide the care that is needed Key features include case studies in every chapter helping students to practically work through difficult scenarios reflective activities that assist readers in thinking critically about their care and how to improve it a holistic approach to palliative care that includes family carers and interprofessional work up to date theory and policy *Palliative Care in Nursing and Healthcare* is suitable for undergraduate nursing students and allied health students and practitioners Michelle Brown is Senior Lecturer at the University of Derby *A Hospice in Change* Martin Lipscomb, 2013-10-15 *A Hospice in Change* Applied Social Realist Theory reports upon a study into aspects of the ways in

which structural and organisational developments professional cultures and bedside or patient focused clinical practice interact within a single UK institution While the findings of this study are time and context specific the events and social processes being described may nonetheless resonate closely with the experience of healthcare practitioners at other hospices both within and without the UK The work examines themes and ideas that hospice and palliative care practitioners as well as those involved or interested more broadly in end of life issues may find relevant It is argued that differential morphogenesis can be identified between structures social and cultural and agents individual and group at an independent healthcare charity in southern England A Hospice in Change connects theory and philosophy with concrete research practice to provide a worked example of Margaret Archer's realist social theory

**Handbook of Palliative Care** Christina Faull, Yvonne H. Carter, Lilian Daniels, 2008-04-15 This handbook is a practical and comprehensive introduction to the field of palliative medicine It provides clear insight into many of the complex issues that arise in the delivery of palliative care and will be an invaluable resource to all disciplines involved in palliative care in hospital hospice and community settings 1st Edition was the WINNER of the 1999 BMA Medical Book of the Year Prize Why you should buy this book Comprehensive and authoritative text with a very practical and thorough approach Written by competent experts in the areas of their contributions New sections on heart failure respiratory failure and end stage renal failure Coverage of medicine management and complementary medicine in palliative care Discusses important areas of audit and ethical issues in palliative medicine The second edition responds to evaluative comments on the first edition in strengthening its multidisciplinary focus and providing a broader professional approach through both the editorial team and contributors It aims as before to embrace practical issues as well as to provide an evidence based and empirical approach From the Preface

**Cicely Saunders and Total Pain** Joe Wood, 2024-11-30 Introduced in 1964 Cicely Saunders' term total pain has come to epitomise the holistic ethos of hospice and palliative care It communicates how a dying person's pain can be a whole overwhelming experience not only physical but also psychological social and spiritual Total pain clearly summarises Saunders' whole person multidisciplinary outlook but is it a phenomenon an intervention framework a care approach or something else This book disregards the idea that Saunders' phrase has one coherent meaning and instead explores the multiple interpretations now current in contemporary professional discourse Using close reading of Saunders' extensive publications as well as archival evidence and Saunders' own personal library it situates the current usage of total pain in wider histories of clinical holism questions its similarity to later ideas of narrative medicine and explores how it might express the ambiguities of bearing witness to pain and vulnerability when someone is dying

**Innovations in Cancer and Palliative Care Education** Lorna Foyle, Janis Hostad, 2017-10-03 This work includes Foreword by Nigel Sykes Medical Director St Christopher's Hospice London This practical evidence based guide has been specifically designed for teachers in cancer and palliative care It is completely up to date and covers the recent complex changes in cancer and palliative care delivery offering a range of different creative approaches Ideal for



training the text includes highlighted key points self help questions for reflection and references where applicable It provides invaluable guidance for all healthcare professionals with palliative care teaching responsibilities including undergraduate and postgraduate healthcare educators and Macmillan lecturers This book gives us a three dimensional view of how to respond to the demands on cancer and palliative care education today set particularly in a British context but of course capable of extrapolation to other settings These three dimensions of innovation can be summarised as What do you teach How do you teach it To whom do you teach it Innovation in all three aspects simultaneously may be difficult to achieve but all who have a responsibility for education are faced with the challenges of making their teaching more effective and demonstrating that they have done so keeping abreast of advancing knowledge and clinical practice and of reaching out to groups of learners who hitherto have been neglected Of significant help to anyone in this field whose concern is the delivery of effective and appropriate education Nigel Sykes in the Foreword

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## **Table of Contents Patient Participation In Palliative Care A Voice For The Voiceless**

1. Understanding the eBook Patient Participation In Palliative Care A Voice For The Voiceless
  - The Rise of Digital Reading Patient Participation In Palliative Care A Voice For The Voiceless
  - Advantages of eBooks Over Traditional Books
2. Identifying Patient Participation In Palliative Care A Voice For The Voiceless
  - Exploring Different Genres
  - Considering Fiction vs. Non-Fiction
  - Determining Your Reading Goals
3. Choosing the Right eBook Platform
  - Popular eBook Platforms
  - Features to Look for in an Patient Participation In Palliative Care A Voice For The Voiceless
  - User-Friendly Interface
4. Exploring eBook Recommendations from Patient Participation In Palliative Care A Voice For The Voiceless
  - Personalized Recommendations
  - Patient Participation In Palliative Care A Voice For The Voiceless User Reviews and Ratings
  - Patient Participation In Palliative Care A Voice For The Voiceless and Bestseller Lists

5. Accessing Patient Participation In Palliative Care A Voice For The Voiceless Free and Paid eBooks
  - Patient Participation In Palliative Care A Voice For The Voiceless Public Domain eBooks
  - Patient Participation In Palliative Care A Voice For The Voiceless eBook Subscription Services
  - Patient Participation In Palliative Care A Voice For The Voiceless Budget-Friendly Options
6. Navigating Patient Participation In Palliative Care A Voice For The Voiceless eBook Formats
  - ePub, PDF, MOBI, and More
  - Patient Participation In Palliative Care A Voice For The Voiceless Compatibility with Devices
  - Patient Participation In Palliative Care A Voice For The Voiceless Enhanced eBook Features
7. Enhancing Your Reading Experience
  - Adjustable Fonts and Text Sizes of Patient Participation In Palliative Care A Voice For The Voiceless
  - Highlighting and Note-Taking Patient Participation In Palliative Care A Voice For The Voiceless
  - Interactive Elements Patient Participation In Palliative Care A Voice For The Voiceless
8. Staying Engaged with Patient Participation In Palliative Care A Voice For The Voiceless
  - Joining Online Reading Communities
  - Participating in Virtual Book Clubs
  - Following Authors and Publishers Patient Participation In Palliative Care A Voice For The Voiceless
9. Balancing eBooks and Physical Books Patient Participation In Palliative Care A Voice For The Voiceless
  - Benefits of a Digital Library
  - Creating a Diverse Reading Collection Patient Participation In Palliative Care A Voice For The Voiceless
10. Overcoming Reading Challenges
  - Dealing with Digital Eye Strain
  - Minimizing Distractions
  - Managing Screen Time
11. Cultivating a Reading Routine Patient Participation In Palliative Care A Voice For The Voiceless
  - Setting Reading Goals Patient Participation In Palliative Care A Voice For The Voiceless
  - Carving Out Dedicated Reading Time
12. Sourcing Reliable Information of Patient Participation In Palliative Care A Voice For The Voiceless
  - Fact-Checking eBook Content of Patient Participation In Palliative Care A Voice For The Voiceless
  - Distinguishing Credible Sources
13. Promoting Lifelong Learning

- Utilizing eBooks for Skill Development
- Exploring Educational eBooks

### 14. Embracing eBook Trends

- Integration of Multimedia Elements
- Interactive and Gamified eBooks

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