

PALLIATIVE CARE NURSING: *A Guide to Practice*

Edited by Sanchia Aranda *and* Margaret O'Connor

Foreword by Patty Hodder



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Patty Hodder
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Foreword

Appropriate care for people at the end of life and support of those who are significant to them have always challenged the practice of nursing.

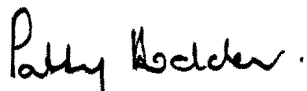
The discipline of palliative care has continued to develop, throughout the world, over the last three decades. Its holistic and person-centred approach has contributed much towards improvement of complex symptom management, general comfort and quality of life for all in the end stage of life, whether that stage be induced by cancer, chronic illness or advanced age.

The publication of *Palliative Care Nursing — A Guide to Practice* is timely and thought provoking. The authors' outstanding contributions deal expertly with a wide range of professional and clinical issues which will help lead palliative care into the 21st century as our way of life and health systems continue to change and be reshaped.

The Australian population is ageing, hospital in the home is a reality, and the role of the family as carers is becoming increasingly vital. Palliative care nurses are challenged

- to find greater creativity in their delivery of services, especially to people living in country Australia;
- to try new ways of working with people from diverse cultures;
- to look with fresh eyes at symptom management;
- to ask the hard questions;
- to undertake research;
- to write about their experiences

I believe that this book will serve as an inspiration to all who read it, especially those who strive to work creatively with people who are dying. I salute all those involved in its production.



Patty Hodder

Registered Nurse (Division 1), Registered Midwife

Certificate in Clinical Pastoral Education

Certificate in Advanced Grief Counselling

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Acknowledgments

The author of chapter 7 and the publisher wish to thank Hyland House Publishing for permission to reprint, on page 114, the poem 'Epitaph' by Kevin Gilbert, from page 94 of *Black from the Edge*.

The Photographs

I began (photo)documenting life in a Brisbane hospice in August 1998. Joanne was 20 and diagnosed with a brain tumour. Within the hospice, it was her age that made her so different from the other patients. Every day I would walk past her room. I wanted to go in but felt I could not intrude. When I finally spoke to Trish (Joanne's mother) I told her that I would like to tell Jo's story, that at the very least this document would say to a future audience that Jo had lived. I told her that, if I began, I would photograph the good and the bad times, that I would not leave the room no matter how sad it became. What I was really hoping to photograph was a miracle.

Joanne was taken home and I continued to document. There was no miracle and Trish never asked me to leave.

David Lloyd, photographer

Preface

Palliative care has been defined by the World Health Organisation (WHO) as '... the active total care of patients whose disease is not responsive to curative treatment'. In addition, '... control of pain, of other symptoms, and of psychological, social and spiritual problems is paramount' (p.11). While palliative care has its foundations in the hospice movement and is primarily concerned with those who are dying, its emphasis has shifted beyond those who are terminally ill. Palliative care has a role to play at all stages of disease processes where issues of pain and symptom management, along with psychological and social support, require attention. This expansion has occurred in recognition that many people diagnosed with non-curative disease will live with the impact and effects of that illness for years and will need intermittent access to palliative care expertise over that time.

Importantly, wherever it is offered, palliative care:

- affirms life and regards death as a normal process;
- neither hastens nor postpones death;
- provides relief from pain and other distressing symptoms;
- integrates the psychological, emotional and spiritual aspects of patient care;
- offers a support system to help patients live as actively as possible until death;
- offers a support system to help the family cope during the patient's illness and in their own bereavement (Commonwealth Department of Health and Family Services, 1998:3).

- Until recently palliative care services have stood apart from mainstream health care and indeed have been criticised for providing luxury services for a minority of the population (Johnston and Abraham, 1995). In most parts of the world palliative care is now being integrated into mainstream health services with emphasis on the use of palliative care knowledge and skills by all health professionals, with support provided by specialists in palliative care. As a consequence palliative care services are being required to demonstrate the impact of their work on patient and family outcomes and to articulate this knowledge and skill to the broader health community. New models of care are emerging with an emphasis on integration and close working relationships between various services providing care to patients and families.

The motivation for this book arises from the need to disseminate palliative care knowledge and skills to nurses working in generalist settings. Our hope is for it to become a guide to practice for nurses new to palliative care or those in other areas of health who are from time to time called on to provide palliative care to patients and families. Our aim has been to provide useful, practical information that will translate easily into a variety of practice settings and serve as motivation for nurses to improve their ability to provide palliative care to people across the health system.

Sanchia Aranda and Margaret O'Connor
Melbourne
January 1999

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