

## Fundamental Aspects of Palliative Care Nursing

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

# **Fundamental Aspects of Palliative Care Nursing**

An evidence-based handbook for  
student nurses

*Second edition*

*Robert Becker*



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## Foreword

Wow! What a roller coaster of emotions this book has evoked. I am really pleased to find out that the reactions I had to death and dying are in fact quite normal. The chapter on bereavement also highlighted and finally put a context to one event that I'll always remember. After my mother died, people I had known all my life seemed to ignore me. I realise now it was because they didn't know what to say, but at the time it's the feeling of isolation that takes a long time to fade. There was also the time I offered a hysterical lady a cup of tea while she was running around the Chapel of Rest. After reading the chapter on communication skills I realise that it was not a completely insensitive thing to say. (This was something that happened in my first year as a student and on my very first placement.)

The book is very user friendly; the text is academic, but written in uncomplicated English, which I found very helpful as I have a form of dyslexia which makes reading difficult at times. It gives an excellent insight into palliative care, and the self- assessment tests are an absolute must so that you can test your understanding of a topic. The three parts help a lot by grouping things together and the chapter headings make it easy to find areas of interest.

For me the book is an excellent survival guide for nursing students with regard to the difficult area of palliative care. Every student knows that death and dying are things that we encounter throughout our three years of training and I really wish I had had this book at the beginning of my training to help guide me through. I will definitely be recommending it to other students and I hope it makes it onto university reading lists.

**Deanna Tompkins**

*Nursing Student, Staffordshire University*

As a student nurse entering my final year of study I was honoured to be asked to write this foreword. It is imperative in my view that end of life care is done compassionately and correctly. It is something that we as student nurses do not look forward to confronting, but will inevitably do so many times during our training and nursing career. It is something we want to do well and something we are petrified of getting wrong. This book guides, advises and supports us through these very difficult times and teaches us ways in which we can do all the right things, answer the difficult questions and provide the best possible

*Foreword*

care for every dying person we encounter. The book also expresses perfectly the importance of this through the medium of the short story to paint a picture at the beginning of each chapter from the perspective of the person who is dying.

The user-friendly style of this handbook enabled me to navigate easily towards any specific area of palliative care I required. The overall format and content not only create a clear guide for student nurses, but also include sections which enhance self-learning, including the 'Reflective activity' and 'Self-assessment test' segments in each chapter. I found the use of different symbols throughout the book very handy to easily locate these exercises.

The reflective activities helped me to build confidence in my clinical practice, by asking me what I would do in certain scenarios. This helped me to visualise situations and to think carefully about how I would handle them. I also found that this was a trigger for reflection on my personal experiences in the clinical placements I have attended to date. I will definitely feel more at ease and in control when confronting similar situations in the future and I will certainly utilise this informative and useful handbook throughout the remainder of my training and take it with me into my nursing career. A great book.

**Abigail White**

*Nursing Student, Staffordshire University*

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## Preface

It is now five years since the first edition of this book was published and whilst the core skills and behaviours required to care for the dying in multiple environments have remained constant, the knowledge base to support this care has developed and changed in some important areas. It is appropriate therefore that this second edition takes a fresh look at the new evidence- and practice-based experience that has become available to inform care in this dynamic area.

The primary focus of the book is now on student nurses, who have many competing demands during their education, but are consistently exposed to palliative care scenarios throughout their three-year training and find such care emotionally exhausting and academically challenging. I also know that they care very much about getting it right, and whilst there are numerous high-quality books on the market that are available to support academic study in this area, this book is currently the only one specifically designed for their learning needs in everyday clinical practice.

Rather than providing a detailed meta-analysis of theoretical and research-based concepts, the emphasis in the text is on dealing with practice-based situations in a sensitive and informed way. This second edition is therefore designed to be a compact, learning-oriented, evidence-based handbook which offers comprehensive, practice guidelines across the spectrum of palliative/end of life care scenarios to provide a trigger and opportunity for reflection and learning.

I have taken the opportunity to redesign the layout of the chapters to make them more structured and user friendly by the use of symbols to help the reader easily locate the relevant information they need. I have also included some educationally important elements, such as learning outcomes at the outset of each chapter to guide the reader, reflective points and activities to help with professional development, and self-assessment multiple choice tests at the conclusion of each chapter to consolidate learning. There is even a true or false quiz offered for those who would like to test their knowledge before or after their studies. The short clinical anecdotes at the outset of each chapter which served well to set the scene in the first edition have been retained and changed only where necessary.

I have also added several new chapters to help readers make sense of the range of new initiatives that have come to the fore in palliative care in the last five years. Even the language has changed and we now hear the term 'end of

## *Preface*

life care' used in many contexts where 'palliative' was used before. Essentially they are one and the same, but government strategy and policy documents have introduced this phrase for a good reason. The term 'palliative', whilst generic in its meaning and intent, has nevertheless become synonymous with hospices, specialisation and above all cancer. There is a real need to find a term that is clearly understood by the general public and embraces caring for the dying of whatever diagnosis in whatever environment. 'End of life care' does just that and signals an intent to meet everyone's needs.

Overall, the integrity of the text remains fundamentally the same. It was the intention with the first edition to produce a book that was very much an evidence-based 'how to do it' text, and feedback from many sources (including the formal reviews), confirmed that this was a successful and much appreciated approach. It is with this in mind that the focus was moved towards student nurses and their learning needs. Post-registration learning opportunities in palliative care abound in the UK for qualified nurses, with a proliferation of study courses available in both the higher education sector and local hospices. Some are tied to academic pathways, while others offer a more flexible online or distance learning approach. Each has its merits and the growth of such educational opportunity has undoubtedly contributed greatly to the high degree of skills employed by nurses in many sectors of healthcare where end of life issues are of importance.

Pre-registration nursing curricula are constantly developing alongside service developments to reflect the need for nurses to be well prepared for the demands of clinical practice in many environments. The learning needs in a palliative context of the next generation of nurses have, however, been systematically ignored by successive statutory bodies. There remains to this day no formal imperative to include any specific end of life care content in the pre-registration nursing curricula on any part of the nursing register. Consequently, provision ranges from the fully integrated and structured module through to the odd lecture given by a local clinical nurse specialist if they can spare the time and have the skills. This is simply not good enough. As any competent educator will confirm, if you can inform, inspire and shape attitudes, skills and behaviours at the outset of a career, then nurses will carry this learning with them throughout their working lives. The potential therefore to empower the role models of the future is enormous, and whilst crowded curricula and complex politics may preclude more formal inclusion of palliative care knowledge in the short term, it is hoped that in some small way this text will fill a much needed gap in the market and provide students of nursing with a user-friendly but challenging reference book that will help them in both their studies and – more importantly – at the bedside of those who die in multiple environments across the healthcare system.

The Nursing and Midwifery Council of the UK published a new edition of their Code of Professional Conduct in 2008, so the links to appropriate

clauses that are relevant to chapter content have been updated accordingly. It is now more important than ever for nurses to be able to utilise the code to support care, so that they can assure themselves of delivering best practice at all times.

Internet content in palliative care has exploded in the last five years and there are now many more highly professional websites that offer a wide range of information for nurses to access to guide practice. The difficulty, however, is knowing which ones are of decent quality. Not all are regularly updated and many have a dual role to provide important information to patients and families as well as to health professionals. Successfully finding your way to one that may prove useful can be a time-consuming and frustrating exercise. Those included in the text have been reviewed carefully for ease of navigation and quality of content.

Some years ago, on a humanitarian aid teaching visit to Russia, I was struggling in the classroom to find the words to express the essence of palliative care and used a simple analogy to get the message across. I likened it to a blend of the head, hands and the heart, the most important of which is the heart. It's a common analogy to which I make no claim, but in the context of the moment it worked well with my Russian audience and has worked well ever since when I've used it in a number of other countries, as well as in the UK. Finding the right words to articulate the real meaning of the palliative approach is not easy, but it's important that we do, so that when challenged to justify our actions in the hard-pressed culture of care we work in we can make a convincing argument that stands up to ethical, financial and humanitarian scrutiny. The argument works both ways of course, and the real test of any civilised society is not only how it deals with the funding and promotion of good health for its citizens, but also how it funds and deals with those who are dying.

To have the opportunity to be at the bedside of someone throughout the final moments of their life is indeed a privilege for any carer. Few professions are allowed the honour of being part of this unique event in the way that nurses are and all of us have a vested interest in getting it right for our patients. One day it will be our loved ones and indeed ourselves who will be the recipients of such care and we would want it to be of the highest standard. This book will hopefully make a small, but significant contribution to helping to mould and shape the attitudes and skills of the nursing practitioners of the future, who may well be the ones at our bedside when a palliative approach beckons. I make no great claims for its efficacy, but I am confident that it can become a useful spanner in the toolbox of knowledge, skills and behaviours that nurses draw on in what is inevitably an emotive and sensitive life event.



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# Acknowledgements

Those of you familiar with the first edition of this book will notice immediately that one of the two original authors is missing from the credits. My colleague Richard Gamlin has taken the opportunity to retire from his position as Senior Lecturer Practitioner in Sunderland and has withdrawn from the production of this second edition. His contribution to the original authorship of this book was considerable and it is appropriate therefore that this is acknowledged. I wish him well in his retirement.

I would also like to acknowledge the support and encouragement given to me from a number of people while this second edition has taken shape. In particular I would like to thank my wife Christine for her wisdom and enduring patience and Maria at Quay Books for her support and enthusiasm. Also Deanna and Abigail for tasking time out from their busy schedules as students to write the foreword and last, but certainly not least, my trusted and vastly experienced education colleagues who were the critical friends with the manuscript when needed and helped enormously to keep me on track.



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## Palliative care quiz

Each of the 50 questions relates directly to material within the text of the book and the whole quiz will take you no more than 20 minutes to finish. Try completing the quiz before you read the book content to see how well you do. Keep a record of your score, and some time later, after you have attempted the reflective activities and the multiple choice questions at the end of each chapter, revisit the quiz. This will give you some idea of how much you've learned. You can also use this evidence within your professional portfolio to demonstrate learning.

	True	False
1. Palliative care is only appropriate in situations where there is evidence of a downhill trajectory or deterioration		
2. In palliative care, dying is seen as a normal life event		
3. The practice of palliative care is compatible with aggressive curative treatment		
4. The extent of the disease determines the method of pain treatment		
5. To palliate means to relieve symptoms by the use of pharmacology		
6. Hospice care is a concept and philosophy rather than a building		
7. Given the choice most people would wish to die in a hospital setting		
8. Competency assessment tools are an objective measure of job performance		
9. Life closure skills, psychosocial care and teamwork are core areas of competency for nurses using the palliative approach		
10. People dying in hospitals feel lonely and isolated from those around them		
11. The provision of palliative care services requires emotional detachment		
12. When encountering death for the first time it is useful to open the window afterwards to release the person's spirit and to bring fresh air around the bedside		
13. Patient choice in how and where people die can be enhanced by the use of care pathways		
14. The Liverpool Care Pathway and Gold Standards Framework have the potential to transform palliative care in the UK		

*Palliative care quiz*

	<b>True</b>	<b>False</b>
15. Drug addiction is a major problem when morphine is used on a long-term basis for the management of pain		
16. Artificial hydration at the end of life can cause the patient more harm than good		
17. Advance directives (living wills) now have full legal status in the UK		
18. During the terminal stages of an illness, drugs that can cause respiratory depression are appropriate for the treatment of severe dyspnoea		
19. Individuals who are taking opioids should also follow a bowel regime		
20. Suffering and physical pain are synonymous		
21. Adjuvant therapies are important in managing pain		
22. The use of placebos is appropriate in the treatment of some types of pain		
23. In high doses, codeine causes more nausea and vomiting than morphine		
24. Morphine is the standard used to compare the analgesic effect of other opioids		
25. Managing symptoms other than pain is mostly about finding the right drug and dosage		
26. The pain threshold is lowered by anxiety or fatigue		
27. Manifestations of chronic pain are different to those of acute pain		
28. Pethidine is not an effective analgesic for the control of chronic pain		
29. Dyspnoea, nausea and constipation are the three most common symptoms reported after pain		
30. The very idea of an emergency in palliative care is a contradiction in itself		
31. Hypercalcaemia can be life threatening if not treated promptly		
32. Spinal cord compression appears rapidly and can resolve itself spontaneously		
33. Telling the patient the truth about their illness if they request it is likely to cause them harm		
34. It's always a good idea when handling sensitive questions to seek more information first from the patient		
35. Silences are difficult and are best handled by using open questioning		
36. The families feelings about the patient knowing their prognosis are always secondary to the patient's wishes		
37. Spiritual care is best delivered by those who know most about it, i.e. ministers of a faith		
38. Agnostics, atheists and humanists are people who can't make their mind up what they believe		



Palliative care quiz

	True	False
39. If nurses are trained better to deliver spiritual care then it would make a big difference to the patients		
40. Essential comfort care around the bedside of the dying are mostly routine functional tasks that are better suited to a healthcare assistants role		
41. Last offices is a routine procedure that is best learnt from a policy manual		
42. During the last days of life, drowsiness associated with electrolyte imbalance may decrease the need for sedation		
43. It is crucial for family members to remain at the bedside until death occurs		
44. Cheyne–Stokes breathing is when the dying person’s respiration becomes intermittent		
45. Natural light and normal conversation around the bedside of a dying person can help both patient and family		
46. Cultural care is full of sensitive pitfalls and it’s best to call in faith leaders and let them deal with it		
47. Truth telling regarding diagnosis and prognosis varies in acceptability in some cultures		
48. Men generally reconcile their grief more quickly than women		
49. The loss of a distant contentious relationship is easier to resolve than one that is close or intimate		
50. Grief can best be described as a time-limiting process occurring through specific stages		
<b>First score</b>		
<b>Second score</b>		



## PART I

---

# Core concepts and developments in end of life care


This part of the book examines the central tenets that comprise the area of nursing we know as palliative care. It has moved a long way in the last decade and the skills that underpin how nurses can use the palliative approach are now much clearer and are examined here. Philosophical understanding of the concept of palliation as an active and dynamic approach has changed little, but this approach is now more systematically utilised by the UK government's End of Life Care Strategy and the development of care pathways. It is further informed by complex and important ethical debate which is constantly evolving and merits close attention. We also know that the drivers behind government strategy are aimed at meeting the needs of all those dying, of whatever diagnosis and in whatever environment; hence the need for a chapter which looks at some of the specific end of life care needs of the most common conditions encountered in clinical practice.



## CHAPTER I

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# What is palliative care nursing?

 *Jenny was a strong, focused person in control of her life and illness. She came into hospital for pain control and we were able to sort that out quite quickly. She began to talk to me about her family, especially her husband, who had not come to terms with her terminal prognosis. Jenny felt she should be strong for him and not let him see her cry. I paused and said 'It's okay to cry you know'. She smiled, went silent for a while and the tears began to flow down her cheeks.*



### Learning outcomes

After reading this chapter and completing the reflective activities the learner will be able to:

- Define the terms 'nursing' and 'palliative'
- Understand how the concepts interrelate to each other
- Identify a range of core statements that characterise palliative care philosophy
- Relate key components of the various definitions of palliative care to nursing practice

### Introduction

This chapter examines the diversity and challenges inherent in the nurse's contribution to palliative care. The art and science of caring for those who are dying and their families has long been recognised as an immensely demanding and rewarding part of health and social care. For nurses it is central to the values and principles that underpin clinical practice.

The science of palliative care has developed rapidly, due mostly to the central role of pharmacological interventions to help control chronic pain and distressing symptoms. This vital and essential aspect of optimising the patient's quality of life has undoubtedly contributed to the widening acceptance of palliative care as a recognised nursing speciality in the UK and beyond. The art

of caring, however, has received significantly less attention, perhaps because of its more abstract nature. It is much more difficult to provide demonstrable clinical evidence of the successful contribution of interpersonal interventions to the overall quality of care to someone who is dying when the outcome is death itself. There is ample evidence, however, that a caring approach which embraces psychological, psychosocial and spiritual support is highly effective and is valued by both patients and families (Beaver *et al.*, 2000).

It can be argued that nursing and palliative care are natural partners in clinical practice and that the knowledge and skills learnt in this area are applicable to all nurses. People die in many environments and all have a right to supportive and palliative care regardless of diagnosis or circumstances (NICE, 2004). The particular knowledge, skills and attitudes needed to deliver quality palliative care will be explored in more detail in Chapter 2, but the values and beliefs that underpin such care are integral to good nursing. Nurses are in a unique situation, as the only real 24-hour carers in the healthcare system to incorporate and develop the principles and practice of the palliative approach into their daily practice where it is appropriate to do so. Therein lays both the paradox and the challenge to those nurses involved in end of life care: how to marry up the art and the science into a cohesive approach that reflects individuality, choices, dignity and compassion in whatever environment the care takes place.

## **Defining nursing**

The activity of nursing is a complex mix of many hands-on skills and personal qualities bound together into an eclectic discipline that is inherently difficult to define. Florence Nightingale herself stated 'I use the word nursing for want of a better'. She went on to comment that 'the very elements of nursing are all but unknown' (Nightingale, 1860). Nursing is concerned with the human condition in times of health crisis and its very essence is therefore bound up in human nature.

The notion of professional caring, the building of therapeutic relationships and the practice of nursing as a regulated profession with definable standards has only been in existence since the beginning of the 20th century. In this time there have been many definitions of nursing published, but in the context of palliative care perhaps the most succinct and relevant one is that written by Virginia Henderson (1997):

Nursing is primarily assisting the individual in the performance of those activities contributing to health and its recovery, or to a peaceful death.

The key phrases that stand out in this definition from a palliative viewpoint are ‘assisting the individual... to a peaceful death’. The phrases suggest ideas of partnership, helping and dignity, all concepts that are central to the palliative approach to nursing.

## **Defining palliative**

The word ‘palliative’ has its origins in the Latin word *pallium* meaning to cloak or cover, and in the context of how cancer was perceived and poorly diagnosed from the Middle Ages until perhaps the latter half of the 20th century, it is perhaps an appropriate description. Even today there are many cancers that grow unseen and without symptoms for some considerable time before the surrounding organs are affected and the person seeks help.

The notion of palliation is in itself very simple to understand. A more contemporary and simple definition is ‘to mitigate the sufferings of the patient, not to effect a cure’ (Macpherson, 2002). If we liken this definition to normal everyday ailments such as a head cold it becomes much clearer. There is currently no known cure for the virus which causes the common cold. Once a cold is contracted, the person experiences a range of symptoms over approximately 3–7 days and hopefully recovers. The experience is uncomfortable, but thankfully not life-threatening most of the time. The only relief obtainable is direct palliation of the most prominent symptoms, in the recognition that cure is not an option, but with the intention to improve our quality of daily life. As an experience it is one we can all relate to and in the context of end of life care the meaning is abundantly clear.

## **Current definitions**

There are two key definitions to take into account. The WHO definition (Box 1.1) dates back to 1989 and was the first to define specialist palliative care. It was updated in 2002 and has been used by healthcare professionals and politicians worldwide to argue for the development of services and to guide practice in palliative care in over 100 countries (WHO 2009). It remains today the most accepted and used definition and the most challenging to those in developing countries where the medical model of care predominates. Take a look at the words and phrases in the definition and you will see why. The emphasis on quality of life and not quantity, the use of the term suffering, which can be both existential and physical and perhaps most of all the affirmation that dying is

### **Box 1.1 WHO definition of palliative care**

Palliative care is an approach that improves the quality of life of patients and their families facing the problem associated with life-threatening illness, through the prevention and relief of suffering by means of early identification and impeccable assessment and treatment of pain and other problems, physical, psychosocial and spiritual

Palliative care:

- provides relief from pain and other distressing symptoms;
- affirms life and regards dying as a normal process;
- intends neither to hasten or postpone death;
- integrates the psychological 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;
- uses a team approach to address the needs of patients and their families, including bereavement counselling, if indicated;
- will enhance quality of life, and may also positively influence the course of illness;
- is applicable early in the course of illness, in conjunction with other therapies that are intended to prolong life, such as chemotherapy or radiation therapy, and includes those investigations needed to better understand and manage distressing clinical complications.

Ref: World Health Organization, <http://www.who.int/cancer/palliative/definition/en/> Accessed: 15 April 2009.

a normal life process, not a medical disease process. Statements such as these still challenge us today, because they force us to think holistically and move away from a medical disease oriented model.

The key phrases and words that stand out from this definition are:

- quality of life of patients and their families
- the prevention and relief of suffering
- relief from pain and other distressing symptoms
- regards dying as a normal process
- neither to hasten or postpone death
- a team approach
- offers a support system... patient and family