

# Palliative Care for Care Homes

*a practical handbook*



Christine Reddall  
*Foreword by Tim Hunt*



CRC Press  
Taylor & Francis Group

## Palliative Care for Care Homes



**Taylor & Francis**

Taylor & Francis Group

<http://taylorandfrancis.com>

# Palliative Care for Care Homes

A PRACTICAL HANDBOOK

**CHRISTINE REDDALL**

*Macmillan Nurse for Care Homes  
NHS Warwickshire*

*Foreword by*

**PROFESSOR TIM HUNT MD, PhD, FRCP**

*Emeritus Consultant in Palliative Medicine  
Brookfields Hospital, Cambridge  
EU Professor in Special Medicine*



**CRC Press**

Taylor & Francis Group  
Boca Raton London New York

---

CRC Press is an imprint of the  
Taylor & Francis Group, an **informa** business



**Radcliffe Publishing Ltd**

18 Marcham Road  
Abingdon  
Oxon OX14 1AA  
United Kingdom

**[www.radcliffe-oxford.com](http://www.radcliffe-oxford.com)**

Electronic catalogue and worldwide online ordering facility.

---

© 2009 Christine Reddall

Christine Reddall has asserted her right under the Copyright, Designs and Patents Act 1998 to be identified as the author of this work.

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, without the prior permission of the copyright owner.

British Library Cataloguing in Publication Data

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

ISBN-13: 978 184619 248 7

Typeset by Pindar NZ, Auckland, New Zealand

# Contents

Foreword	vii
Preface	viii
About the author	xii
Acknowledgements	xiii
Dedication	xiv
<b>1</b> Introduction	<b>1</b>
<b>2</b> What is palliative care?	<b>3</b>
<b>3</b> What is a Macmillan nurse?	<b>7</b>
<b>4</b> What is a hospice?	<b>12</b>
<b>5</b> What is cancer?	<b>17</b>
<b>6</b> What is a syringe driver?	<b>23</b>
<b>7</b> Symptom control	<b>30</b>
<b>8</b> Breathlessness (dyspnoea)	<b>33</b>
<b>9</b> Constipation	<b>37</b>
<b>10</b> Fatigue	<b>40</b>
<b>11</b> Mouth problems	<b>44</b>
<b>12</b> Nausea and vomiting	<b>48</b>
<b>13</b> Pain	<b>52</b>
<b>14</b> Difficulty with eating and drinking	<b>61</b>
<b>15</b> Other symptoms	<b>64</b>
<b>16</b> Difficult questions	<b>73</b>

<b>17</b>	<b>Spiritual distress and palliative care</b>	<b>82</b>
<b>18</b>	<b>The dying process</b>	<b>86</b>
<b>19</b>	<b>A good death</b>	<b>93</b>
<b>20</b>	<b>After death</b>	<b>97</b>
<b>21</b>	<b>Acute medical events in palliative care</b>	<b>100</b>
<b>22</b>	<b>Acute terminal events in palliative care</b>	<b>103</b>
<b>23</b>	<b>Morphine and pain patches</b>	<b>106</b>
<b>24</b>	<b>Dementia</b>	<b>111</b>
<b>25</b>	<b>Palliative care for people with learning disabilities</b>	<b>118</b>
<b>26</b>	<b>The unexpected</b>	<b>126</b>
<b>27</b>	<b>Older people in care homes</b>	<b>133</b>
<b>28</b>	<b>Benefits and grants in palliative care</b>	<b>137</b>
<b>29</b>	<b>Care pathways in palliative care</b>	<b>142</b>
<b>30</b>	<b>Advance care planning</b>	<b>147</b>
<b>31</b>	<b>Palliative care education</b>	<b>150</b>
<b>32</b>	<b>Looking after yourself</b>	<b>152</b>
	<b>Further reading, useful websites and other resources</b>	<b>154</b>
	<b>Initiatives to enhance patient care and carer support in care homes</b>	<b>158</b>
	<b>Index</b>	<b>161</b>

# Foreword

The growing and undisputed importance of care homes in today's social fabric cannot be exaggerated. This book is directed at carers who are at the front-line of such care. Here we have a text for those who want to roll up their sleeves to look after those in care homes. It is not for the theoretician and avoids the vacillation and pontifical writing often associated with palliative care. A strong practical approach is stamped throughout the book in a language and style to embrace carers. It is written by someone who has immersed herself in actual empathetic practical care. Her extraordinary keenness and warmth radiate from each page, and her very personal approach, while alien to much professional expression, is written without discomfiture as she writes about her father, his illness and death. It is these penetrating personal experiences that fuel her motivation to understand and help other carers.

Many avert their eyes from the silent suffering and often distressing situations that we may witness in care homes and many forget the praise and respect which we should accord to carers. We owe much to others, especially to the older person. They have nurtured us and striven to give us a better life than they experienced; they have fought for our relative freedom and each of us tomorrow will need care.

This book will help the elderly, all persons in our care, their relatives and close friends and above all the carers who deserve our unstinted support and unreserved acclamation.

**Professor Tim Hunt MD, PhD, FRCP**  
**Emeritus Consultant in Palliative Medicine**  
**Brookfields Hospital, Cambridge**  
**EU Professor in Special Medicine**  
*October 2008*

# Preface

This is a resource book that provides information on palliative care. It is designed primarily to help carers who work in care homes of all categories. To my knowledge, it is the first book written solely for carers working in care homes that addresses the issues of caring for individuals with palliative care needs. However, people to whom I have spoken about this book, or who have read parts of it, have all said that it would also be a helpful resource for non-professional family carers who are caring for a family member in their own home.

The book is designed to be readable by all levels of carers, and I have endeavoured to keep the language and text as 'non-medical' as possible. I have pondered over the most appropriate name for the groups of people I shall be discussing in this book, as it is necessary to maintain consistency of that name throughout the text. In the various care homes that I visit in my work, 'patients' are referred to as 'residents', 'clients' and 'service users'. 'Carers' are variously referred to as sisters, matrons, staff nurses, auxiliary nurses and support workers. Therefore, for ease of reading, I have chosen to refer to all those who care for people as 'carers', and all those who receive care as 'patients'. When referring to an individual, I use either gender indiscriminately. All illnesses that fall within the category of palliative care are referred to as 'life limiting.'

In this book, each chapter explores an aspect of palliative care in relation to the type of patients who are cared for in a care home, and the carers who provide this care on a daily basis. The reader can of course dip in and out of the various chapters according to the information that they need at the time.

My background is in nursing, and at the time of writing I have been a nurse for 37 years. I started off as most nurses do, working on a variety of wards, gaining experience and deciding which areas of nursing I found most

rewarding. I soon settled into care of the elderly – known as ‘geriatrics’ in those days. Through working in this area, I developed an interest in palliative care and embarked on a career path that would eventually gain me a post as a Macmillan nurse. The path was not easy, and involved doing courses, obtaining a degree, writing articles, getting myself known and applying for jobs. My determination eventually paid off, and in 1995 I obtained my first post as a Macmillan nurse. Since then, my passion for palliative care has gone from strength to strength, and at the time of writing I am employed by Warwickshire NHS Trust, working as a Macmillan nurse for care homes across Warwickshire. I have a combined clinical and educational remit, and find myself in a thoroughly rewarding job that combines my two favourite areas of nursing – palliative care and care of the elderly. It is this role that has prompted me to write this book. While meeting the many carers who work in the homes, and providing them with palliative care education, I have listened closely to their needs. It is my belief that the skills possessed by these carers who work in care homes, and the care that they provide for our ever increasing elderly population, are often underestimated. (I should add here that although the elderly make up the largest proportion of residents in care homes, increasing numbers of younger people are being cared for in these establishments. Indeed, of the 21 care home residents currently on my caseload, three are under 50 years of age.)

During my early nursing years I worked mainly with the elderly, and although I found this both interesting and rewarding, compared with my colleagues who were working in Accident and Emergency and other more acute settings, I was often made to feel that I was working in a ‘backwater’ area of nursing. ‘Geriatric nursing’ was seen as easy, not requiring much in the way of brain power, and a thankless task.

However, over the years, I have come to realise that the elderly in particular often have very complex needs, as they are generally suffering from more than one illness, and frequently taking a cocktail of medication that has been added to over the years. It also became apparent to me that caring for elderly people during their illness requires very special skills, such as the need to be aware of a host of different diseases, different medications and dose ranges, and the need to deal with mental and physical impairment.

Because of the ageing general population, more and more care homes are finding themselves caring for patients with complex life-limiting conditions, such as cancer, motor neurone disease, diabetes, stroke and heart failure, to name just a few. This is happening even in the care homes (sometimes called ‘residential homes’) where the carers are mostly untrained. There are also many homes where carers help to support people with learning disabilities.

These types of home are often conventional houses situated in residential areas, usually housing an average of between two to eight residents with learning disabilities plus live in carer(s).

Care homes must observe many rules and regulations which are laid down by their governing body. Much of their training (e.g. in lifting and handling, wound care and food hygiene) is mandatory. However, despite the increasing numbers of patients in care homes who are suffering from a range of life-limiting illnesses (such as those mentioned above), palliative care training is not mandatory. It has therefore been very enlightening to find that, since working within this role, I have been inundated with requests to provide palliative care training. I have been astounded by the amount of interest in palliative care, to the extent that many nurses attend unpaid education sessions, in their own time, and often after working a night shift. While providing these education sessions, it became apparent to me that carers are often unclear about the real meaning of 'palliative care', many believing that palliative care refers specifically to care given to a person who has cancer, or during the final days of life. Confusion also surrounds the role of the Macmillan nurse and the hospice, and how the various services that come under the umbrella of palliative care work together. The more I have visited and helped to support care homes in my capacity as a Macmillan nurse, the more I have discovered about the care that is provided in these environments, and how isolated many of the carers are from study days, sources of new information and other resources to keep them up to date.

I am aware that for huge numbers of care homes around the UK there may seldom be the opportunity to undertake training in palliative care, and although the situation is a lot better than it used to be, there are still not many nurses currently working in roles similar to mine. Hence the need for this book!

The content of this book is not new. It is not full of mind-blowing technology or medical jargon, it does not contain a great deal of referenced material, nor does it include many charts or facts and figures. Much of the information in this book can be sourced elsewhere. You could buy a palliative care book on symptom control, communication, cancer, etc. You could send away for literature about Macmillan nurses, hospices and benefits. Or, if you are computer literate, you could find all kinds of information about palliative care on the Internet. What I have done is to pool all the information together in one book, using information drawn on my own experience of palliative care in this area, backed up by case histories of real people (their names have been changed, of course) and my experience of working closely with a large number of carers. I have tried to put myself in the shoes of carers, especially



those without medical training, and to consider what they might want to know when caring for patients with a life-limiting illness.

I know that care homes often receive much criticism from various sources, and, as in every walk of life, there is good and not so good practice. However, I have to say that during my current role, I have seen far more good than bad. Since I have been working in this area, it has been a real privilege to help to convey the principles and practice of palliative care to the carers who work in care homes. The provision of good general palliative care that has prevented a patient from being admitted to hospital in their last days of life is a huge achievement that should always be applauded.

So, to all carers who are dedicated to working in a care home, I take my hat off to you. If you are one of these carers, just by getting hold of this book you are showing interest and compassion in your caring role. So take heart – you do a great job and provide care for a wide range of patients with differing needs. Read the book, boost your confidence and carry on doing a good job.

**Christine Reddall**  
*October 2008*

## About the author

Christine has been a qualified nurse since 1973. Having spent a large part of her nursing career in care of the elderly, she developed a passion for palliative care and her ultimate goal was to become a Macmillan nurse. She achieved this goal in 1997, following completion of a degree in palliative care. After working as a community Macmillan nurse for 7 years, she was delighted to be appointed Macmillan Nurse for Care Homes across Warwickshire. This was a brand new post, with a 50% clinical and 50% educational remit. Over the past 4 years, Christine has focused on developing this service and enhancing the palliative care that is delivered in care homes. Some of her work has been published in nursing journals, but this is her first book.

# Acknowledgements

I would like to thank all of the care homes across Warwickshire that have given me such a wonderful insight into the care that they provide for their patients. You know who you are, and I think you are wonderful.

I wish to thank my sister Sue and friends Carol and Barbara for proofreading each chapter as I went along. As non-medical people, their input was valuable in helping to prevent this book from becoming too medical. If they didn't understand something, it wasn't included!

A special thank you is due to my daughter Lisa, for formatting the manuscript.

I also owe a big thank you to my husband Phil, for his encouragement and constant nagging to 'turn off my work phone' so that I could get down to writing. He also painstakingly reproduced my hand-drawn charts in formats that could be printed.

I would like to remember a very special friend, Frankie, who died in a care home in 2006 aged 99 years. She was suffering from a life-limiting illness, yet she bore it with dignity and a smile (most of the time). Despite her frailty, she was a strong voice when it came to deciding how she wanted to be cared for, and I know she will be long remembered by all who had the privilege of caring for her.

# Dedication

This book is dedicated to my father, who died from mesothelioma in March 2006. I know that if he were alive today he would be so proud that I had written this book.

His illness is part of the reason why I chose to write in the way that I have. Like myself, Dad's family and friends struggled to understand what was happening to him, and what they could do to help. My mother was with him when he died, and she has struggled to come to terms with what happened at the end. Of course I struggled, too, but in a different way. Like my family, I hated seeing what the illness was doing to my father, and I hated the fact that he was going to die, but unlike my family, I struggled because I knew so much about his illness and I knew what was happening. In some ways, having this knowledge both hindered and helped me. It hindered me because I just wanted to be a daughter – not a nurse. However, it also helped me because I knew what the disease was doing to him, and I was able to help my family to understand this as well.

Because this book is dedicated to my father, I would like to tell you about our wonderful trip together.

Dad's two loves in life were his family and going on holiday. He and my mother had recently celebrated their diamond wedding anniversary and were enjoying a holiday with myself and my husband on a short visit to Amsterdam. We were talking about holidays when my father voiced a wish to go to India to see a tiger. After much joking about the easier option of going to London Zoo, my well-travelled, active, 82-year-old mother decided that this type of jungle adventure was a little beyond her capabilities. So I, having the same sense of adventure as my father, and at the tender age of 53 years, said that I would love to go with him. As soon as we arrived home from Amsterdam, my father embarked on a trawl of holiday brochures and trips to the library to research

the area. He finally decided on a trip to Nepal that included a search for the Bengal tiger! He took great pleasure in organising everything for us, and as I was still working, I willingly left him to it. We eventually received our date of departure – 21 February 2005. We flew business class and enjoyed the luxury of this, as it was a new experience for both of us. In Kathmandu, we met up with our fellow travellers and our guide. My father and I went on elephant safaris at the crack of dawn, flew over Mount Everest, went horse riding (my father's first and only experience of this), and saw the magnificent sight of the sun rising over the Annapurna mountain range. While we were waiting to get on a river boat, a rhinoceros appeared out of the bushes. Our guide told us not to panic, but said that if it did charge, we must all run in the opposite direction, throwing off items of clothing to distract it! Fortunately, it didn't charge and we all got safely on to the boat. How we laughed at the thought of us, and all our colleagues aged 60 years or over, running and disrobing at the same time! I have to say at this point that my father was 83 years old and fit as a flea! I was the youngest member of the group. However, I had suffered a viral chest infection prior to the holiday, and I was the one wheezing and coughing. My dad was skipping along like a mountain goat, helping all the other 'elderly people' (most of whom were considerably younger than him) and thoroughly enjoying every minute!

Sadly, despite many jungle outings, we did not see a tiger, just a paw print!

We returned from this wonderful holiday and my family asked what had happened to my father, because he looked 10 years younger. (They didn't make any such comment about me!) The next few months were spent regaling others with our adventure, and planning the next trip, in 2006. By the end of the year, the second trip was booked and paid for. A slightly different one this time, but still with the aim of seeing a tiger! Sadly, it was not to be. My wonderful father, who had been so fit and healthy, became ill two weeks after Christmas. He was diagnosed with mesothelioma (a malignant disease caused by exposure to asbestos). After a stay in hospital to drain the fluid off his chest, he returned home and, very typical of the way he had always been, he tried to be as independent as possible. Sadly, he was so short of breath that many of his activities had to be curtailed. He could no longer walk his dog, and driving was out of the question. This was the opposite of how he wanted to be, and I knew in my heart that his illness would not last long because he couldn't bear the thought of becoming an invalid. Although none of us wanted him to die, we all knew that it would be better for it to happen sooner rather than later – before he became so ill that he was unable to do anything for himself.

Up until the day he died, my father remained 'in charge.' He even managed

to get to the hospital to be marked up for a course of radiotherapy the day before he died (albeit with a cortege of helpers and a cylinder of oxygen!).

The night before he died, my mother suggested that she should stay with him, but he insisted that he was OK and that she must go to bed. The next morning, he asked my mother for a cup of tea, which he insisted on holding himself. He was very weak by then and, as my mother later described, he started to shake and the tea spilled on to his chest. Minutes later he died. For a long time my mother has felt guilty (and maybe even still does) about not staying with him overnight, and about allowing him to hold a hot cup of tea on his own. However, I believe that my father knew exactly what he was doing and exactly what he wanted, because that was the way he had always lived. I often tell my mother that my dad died as he had lived – independent, in charge and determined right up to the end!

As I said earlier, my father had a wonderful sense of adventure. Just before he died, he said to me, 'Well, love, I'm off on a different adventure this time.' I remember those words with such comfort, and often quote them to others who are facing bereavement.

When I finish this book, I plan to return to Nepal with my husband on the same trip as that which my father and I made, or a similar one.

And Dad – I am determined to see a tiger!

# Introduction

When we think of the term 'care home', we usually associate it with the elderly. Equally, when we talk about 'life-limiting illnesses' and 'palliative care' in care homes, these terms are mostly associated with the elderly. However, increasing numbers of younger people are being cared for in this type of environment, especially those with physical disability and learning disability, and some of these individuals have illnesses that require palliative care. Therefore all carers who work in care homes should be aware of the meaning of palliative care, and of all the different aspects that contribute to the provision of palliative care.

Carers often struggle when looking after a patient who is suffering from a life-limiting illness or a patient who is clearly going to die soon. They may feel uncertain about talking to that person about their illness, fearing that they won't understand, or that the truth would be upsetting to them. They may be frightened about the emotions that could surface when talking to patients and their families about cancer and other illnesses.

Some carers have difficulty talking about serious illness to one another, especially if that illness is cancer. The word 'cancer' seems to scare many people more than some of the other life-limiting illnesses that can cause similar symptoms and debility. However, not talking often causes more fear and distrust and makes caring very difficult for all involved. There is also a danger of creating a 'conspiracy of silence', where professionals, family and friends all know about the illness and impending death, but will not talk about it in the presence of the patient or each other. It may seem that by not talking about it, each is protecting the other from unnecessary distress. However, just because someone – whether they are the patient or the carer – is not talking about the illness doesn't mean that they aren't thinking about it. And not being able to voice concerns will ultimately lead to escalating confusion and distress for all concerned.



I have often heard carers say, 'Surely he would be better off in a hospice where they give proper palliative care.' Of course hospices do provide excellent palliative care, but they do not have the capacity to provide care for everyone with a life-limiting illness. This is why it is so important that the principles and practices of palliative care are taught, understood and used in hospitals and community settings such as care homes. If you ask most people where they want to be cared for in the last months or weeks of life, the majority of them would say in their own home. For many elderly people in particular, the care home is their home and this is where they want to stay and be cared for.

People are living longer and longer, and as they get older they tend to suffer from multiple and chronic illnesses. Consequently, the care that they require becomes more complex. Regardless of how old a person is, they have a right to be treated with the same care and compassion that a younger person would receive. They have the right to be heard and to be able to make their own choices about their care. Sadly, however, this does not always happen.

If you are a carer reading this book, whether or not you are a trained nurse you are certainly not alone in feeling less than adequate at times. This is why I wrote this book – to help carers who work in care homes to feel valued and confident in providing palliative care for their patients. I fully appreciate that carers who work in care homes are often busy, having a million and one jobs to do. However, good palliative care need not be any more time consuming than the general care that you provide on a daily basis. Good palliative care is not about how *long* you take to provide care for the patient, but how *well* you provide that care.

*Remember:* Older people have a wealth of life experience, they each present in their own unique way, and they were young and able once. Hopefully, all of us will live to old age, and we will then want to be treated with dignity and respect. Taking all of this into consideration, you can see how care homes are in a unique and privileged position to provide palliative care for our older population.