Compassionate Person-Centered Care for the Dying

Bonnie Freeman, DNP, ANP, RN, ACHPN

A milestone resource for palliative care nurses that facilitates evidence-based compassionate and humanistic care of the dying

"...a valuable contribution to the evolving field of palliative nursing care. It is authored by a model for this field, Bonnie Freeman, and brings to the bedside what her practice embodies—evidence-based clinically expert care....The CARES tool is a long-needed resource and we are all grateful to the author for moving her passion to paper. It will touch the lives and deaths of patients, families, and the nurses who care for them."—Betty Ferrell, PhD, RN, MA, FAAN, FCPN, CHPN

Professor and Director, Division of Nursing Research and Education
City of Hope National Medical Center

From the Foreword

This groundbreaking reference for palliative care nurses is the first to provide realistic and achievable evidence-based methods for incorporating compassionate and humanistic care of the dying into current standards of practice. It builds on the author's research-based CARES tool; a reference that synthesizes five key elements demonstrated to enable a peaceful death, as free from suffering as possible: comfort, airway management, management of restlessness and delirium, emotional and spiritual support, and self-care for nurses. The book describes, step by step, how nurses can easily implement the basic tenets of the CARES tool into their end-of-life practice. It provides a clearly defined plan that can be individualized for each patient and tailored to specific family needs, and facilitates caring for the dying in the most respectful and humane way possible.

The book identifies the most common symptom management needs in dying patients and describes, in detail, the five components of the CARES paradigm and how to implement them to enable a peaceful death and minimize suffering. It includes palliative care prompts founded on 29 evidence-based recommendations and the National Consensus Project for Palliative Care Clinical Practice Guidelines. The resource also addresses the importance of the nurse to act as a patient advocate, how to achieve compassionate communication with the patient and family, and barriers and challenges to compassionate care. Case studies emphasize the importance of compassionate nursing care of the dying and how it can be effectively achieved.

Key Features:

• Provides nurses with a clear understanding of the most common needs of the dying and supplies practical applications to facilitate and improve care
• Clarifies the current and often complex literature on care of the dying
• Includes case studies illustrating the most common needs of dying patients and how these are addressed effectively by the CARES tool
• Based on extensive evidence as well as on the National Consensus Project for Palliative Care Clinical Practice Guidelines

11 W. 42nd Street
New York, NY 10036-8002
www.springerpub.com

9780826122476

Compassionate Person-Centered Care for the Dying
Bonnie Freeman, DNP, ANP, RN, ACHPN, is an adult nurse practitioner in the Department of Supportive Care Medicine at the City of Hope National Medical Center in Duarte, California. She is involved with treating the symptom management needs of many chronically and terminally ill individuals diagnosed with various forms of cancer. Dr. Freeman trained at such excellent facilities as the in-patient units at San Diego Hospice and the Institute of Palliative Medicine in San Diego, California, and the home care hospice program in Owensboro, Kentucky. While in Kentucky, she completed her advanced practice clinical training for adult nurse practitioners with a specialty focus on palliative care through Vanderbilt University in Nashville, Tennessee. This program exposed Dr. Freeman to current concepts in caring for the dying, and enhanced her already significant clinical experience caring for dying individuals acquired from over 30 years working in critical care. Dr. Freeman obtained her MSN from Indiana Wesleyan University, and her DNP from Azusa Pacific University in Azusa, California.

Contributors

Tracey Das Gupta, MN, RN, CON, is director of Interprofessional Practice at Sunnybrook Health Sciences Centre in Toronto, Ontario, Canada. She is also the colead of the Quality Dying Initiative with Dr. Jeff Myers. Tracey has been passionate about health care, quality of life, and leadership since becoming a nurse in 1991. Her decision to become a nurse was influenced by her father who lived with muscular dystrophy. Ms. Das Gupta has fulfilled various frontline nursing roles along the continuum of care and has had the opportunity to continue to grow in leadership roles such as educator, professional practice leader, and director of nursing practice. In her current role, she also provides leadership for the development and implementation of Sunnybrook’s interprofessional care (IPC) strategy.

Margaret Fitch, PhD, MScN, is a nurse researcher and holds an appointment at the Bloomberg Faculty of Nursing and School of Graduate Studies at the University of Toronto. She also serves as expert lead for cancer survivorship and patient experience for the Person-Centered Perspective Portfolio of the Canadian Partnership Against Cancer. She is also editor-in-chief for the Canadian Oncology Nursing Journal. Dr. Fitch has an extensive publication record based on her many years of research regarding patient perspectives, coping and adaptation with illness, and screening for psychosocial distress. She has particular expertise in measurement and evaluation, qualitative methods, and knowledge integration. During her career, she has held clinical and administrative positions and has maintained an ongoing role in education of both undergraduate and graduate students and health professionals in practice.
Compassionate Person-Centered Care for the Dying

An Evidence-Based Palliative Care Guide for Nurses

Bonnie Freeman, DNP, ANP, RN, ACHPN
I would like to dedicate this book to Dr. Chatchada Karanes for her inspiration and trust in me; Betty Ferrell, for her support and faith in me; my husband Allen, for his understanding and love; my daughter Anna, for always being there for me; the administrators of the Departments of Nursing and Supportive Care Medicine at the City of Hope; and the faculty at Azusa Pacific University, for their never-ending faith and encouragement in promoting the use of the CARES tool.
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Foreword

Caring for people in the final hours of their lives is one of the most important and sacred aspects of nursing practice. This care at the end of life is truly whole-person care, attending to physical, psychological, social, and spiritual well-being. It is also what Florence Nightingale noted as the art of nursing.

This book on CARES is a valuable contribution to the evolving field of palliative nursing care. It is authored by a model for this field, Bonnie Freeman, DNP, ANP, RN, ACHPN, and brings to the bedside what her Practice embodies—evidence-based clinically expert care. I had the privilege of serving on Bonnie’s capstone committee for her Doctor of Nursing Practice degree as well as observing her in practice at the City of Hope Medical Center. Importantly, the CARES tool is far more than a product of her doctoral studies. It is the product of decades of nursing practice and her deep compassion for patients and families. It is wonderful to see brilliant nurses find each other across countries, and thus the collaboration of Bonnie with Margaret Fitch, PhD, MScN, and Tracey Das Gupta, MN, RN, CON, has now given birth to this excellent book.

A very important aspect of the CARES tool is that it acknowledges both the profound privilege we have in caring for patients at the end of life and also the compassion fatigue of nurses as a result of this work.

The CARES tool is a long-needed resource and we are all grateful to the author for moving her passion to paper. It will touch the lives and deaths of patients, families, and the nurses who care for them.

Betty Ferrell, PhD, RN, MA, FAAN, FCPN, CHPN
Professor and Director
Division of Nursing Research and Education
City of Hope
National Medical Center
Duarte, California
Preface

The CARES tool was designed to be an acronym-organized and condensed education reference that provides prompts and recommendations to consider when caring for the dying. It is based on five common symptom management needs typically addressed when caring for the dying, identified from a literature review and analysis. The CARES tool was introduced to health care providers through poster presentations at national conferences in 2012, and in an article titled “CARES: An Acronym Organized Tool for the Care of the Dying,” published in the Journal of Hospice and Palliative Nursing in May 2013.

The CARES tool article was the most downloaded article on MedScape in May 2013. Response to the CARES tool continues to be very positive, and I continue to provide lectures and assist in the training of nurses in end-of-life care. Many requests continue to be made to use the CARES tool for end-of-life education and training at other facilities throughout the United States and Canada. It provided a focus for the end-of-life house-wide initiatives developed at Sunnybrook Health Sciences Centre in Toronto, Canada, which is shared in Chapters 22 and 23.

Caring for the dying and their families can be one of the most emotionally fulfilling, personalized, and loving acts a nurse can provide. As Dr. Timothy Quill (1996) noted, the skills required to care for the dying are not high tech, but they are definitely high touch. The care nurses provide the dying and their families can change us as nurses and as human beings. Nurses can learn what is truly important in life and cannot help but be moved by the expressions of love and loss they will witness. The ability to empathize and provide compassionate care ultimately spills over into our daily interactions. It is common that nurses begin to view coworkers, their own families, and even the occasional angry car driver differently. They learn to embrace what is really important.
Preface

I hope to instill a sense of importance and urgency in the readers of this book. There is much to learn about providing quality evidence-based care for the dying and their families. This book about the CARES tool is unique in this regard as it attempts to convey essential information on how to effectively care for the dying in a condensed and readily applicable format for the bedside nurse. Stories and examples are provided to emphasize the importance of the nursing care required to effectively manage this much underserved growing population.

Quality evidence-based care of the dying is a special skill and can be developed and improved on with knowledge and experience. Additionally, nurses need to support each other and accept this very great challenge given to us by our aging society. Death must be accepted as a fact of life and honored. It is my hope that the use of the CARES tool will provide some guidance with this effort.

The chapters of this book help to dissect the CARES tool and show in detail the basis for its development and its many applications. Each chapter contributes to an example scenario about Steven, an actively dying 20-year-old young man with lymphocytic leukemia, whose treatment course was complicated by the development of graft-versus-host disease of the lung after bone marrow transplant. A basic overview of chapter content includes:

- A general background and the establishment of the CARES tool are found in Chapters 1 to 5.
- A detailed breakdown of the CARES tool by sections (comfort, airway, restlessness and delirium, emotional and spiritual support, and self-care) is discussed in Chapters 6 to 11.
- The theoretical foundation of the CARES tool is shared in Chapter 12.
- The need for patient advocacy and strong communication skills is emphasized in Chapters 13 and 14.
- Chapters 15 and 16 explore what can be done to promote a peaceful death, and case studies are provided.
- Chapters 17 and 18 address the changes in our culture that must occur and the new role of the doctor of nursing practice (DNP).
- Chapters 19 through 21 examine how the use of the CARES tool can impact nursing care and encourage end-of-life care involvement by other health care providers, and how hope can be nurtured for the dying.
- Chapters 22 and 23 provide insight into CARES tool application strategies employed at Sunnybrook Health Sciences Centre in Toronto, Canada.
- Chapter 24 summarizes the example scenario of Steven’s final journey and the individualized care he and his family were given in an effort to provide a peaceful and loving death.
- Chapter 25 provides some recommended websites, readings, and references to continue the reader’s education on evidence-based compassionate care of the dying.
Hospice, palliative care, and end-of-life care are complex medical specialties. The CARES tool does not provide a complete listing of all symptom management needs that could occur for the dying and their families. It attempts to address the most common issues encountered during the dying process. The CARES tool can only be fully understood and embraced as standard practice if additional end-of-life education is obtained. Ultimately, it is hoped that the CARES tool will empower nurses and health care staff to act as strong patient advocates, improve communication, provide individualized family-driven care, and employ the greatest gifts they have to offer a dying person and his or her family: the gift of their presence and their humanity (Puchalski & Ferrell, 2010).

In an effort to make the content of the CARES tool more accessible, a smartphone download is now available from Springer Publishing Company with the purchase of this book. Please visit http://www.springerpub.com/compassionate-person-supplemental-materials to access this material.

Ultimately, the CARES tool was designed to address methods to help health care staff reduce if not eliminate the many treatable causes of suffering that can occur during the dying process. I close with Dr. Ira Byock’s (2012) haunting observation that motivated me to develop the CARES tool:

There are worse things than having someone you love die. Most basic, there is having the person you love die badly, suffering as he or she dies. Worse still is realizing later on that much of his or her suffering was unnecessary. (Preface)

Bonnie Freeman

REFERENCES


Prologue: Reflections on End-of-Life Care

Death was an all too common outcome in the critical care units where I worked for the majority of my nursing career. I did not know that my desire to comfort and console the dying and their families would become a specialty form of care for me in the future. I believed it was just part of my nursing role to emotionally comfort individuals under my care and their families. The time I took to listen, allow individuals to speak of their fears, and sit quietly holding their hand was as important to me as any procedure or technical task. I simply gravitated to the care of the dying and their families, and was humbled and honored by the opportunity to help.

I believe the greatest training I obtained about caring for the dying came from the personal perspective I gained from caring for my parents and family as my mother died. I became acutely aware of how nurses interacted with the dying and their families during the death of my 48-year-old mother from lymphoma in 1986. I was 26 years old and a new nurse. I was totally naive when it came to caring for the dying; it was never discussed in nursing school, and I had no exposure to the specific skills that would be required. Unfortunately, I soon learned firsthand what not to do, and received my first life experience of how it felt to be abandoned, treated as insignificant, devalued, and ignored.

My mother was placed in a back hall, farthest from the nurse’s station so as not to upset anyone while she was actively dying. Any call to the nurse’s station for help was met with exasperated sighs, and then silence. I will always remember the overwhelming sense of helplessness, sadness, and loss that accompanied my mother’s dying process. I remember an agitated respiratory therapist who informed me and my family that any further suctioning to decrease the bloody oral secretions produced by my mother would “just make her die faster,” and that we “needed to stop calling because others that were more healthy need help.”

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I remember the oncologist who insisted he could still “cure” my mother—now with metastasis to the brain, bone, liver, kidneys, and lungs; with one blown pupil, unresponsive, and having Cheyne–Stokes respiration. How he begged my father and me not to “give up” on my mother, and how furious he was when we made her a do not resuscitate (DNR) and refused transfer to the intensive care unit. The oncologist angrily told my father and me that we were “killing her,” and refused any further involvement in my mother’s care.

My family and I wished only for our mother to die peacefully. It would have been so comforting to have had just one nurse take the time to be with us. I knew nothing more could be done, but recognized a deep need to know that someone else cared. We needed someone to sit and listen, to acknowledge our fears and pain, and to provide some small acts of compassion so we didn’t feel so alone and abandoned. We needed someone to acknowledge our suffering and somehow validate our loss.

The lack of compassion and humanity caused me to feel like I was nothing and that my mother was nothing, and that none of us mattered. I will always remember the overwhelming grief and fear that I would never stop crying. I remember wondering how the nurses could ignore our suffering, and that they just didn’t seem to care. It was the first time in my short career as a nurse that I was ashamed of my profession.

This personal experience motivated me to vow I would never allow a dying individual under my care or his or her family experience what I had endured. I believe it would have taken so little to make a difference. The emotional impact of having someone you love die before you is painful beyond words, and the abandonment I experienced during the last hours of my mother’s life will forever be embedded in my memory.

This personal life experience motivated me to become the kind of nurse I wished had been there for me. Now, with each opportunity to comfort and assist a dying individual and his or her family, a personal healing takes place for me.

The development of the CARES tool was an extension of my vow. I began to realize that nurses were not intentionally distant or unfeeling when it came to caring for the dying; they just didn’t know what to do. The CARES tool was developed to assist in providing this needed information in an easily accessible form, and to stimulate a desire to learn more about care of the dying. I continue to encourage nurses and anyone involved in the care of the dying to seek additional training from programs such as the End-of-Life Nursing Education Consortium (ELNEC).

I am humbled and honored by the opportunity to make a difference in the lives of the families of the dying, and have now found additional joy helping nurses improve their end-of-life care.

Bonnie Freeman
I had the pleasure of being introduced to Bonnie through my role as colead for the Quality Dying Initiative (QDI) at Sunnybrook Health Sciences Centre (SHSC), in Toronto, Ontario, Canada. In our organization, we decided that it was imperative for us to pay very close attention to the quality of the dying experience for all persons throughout the hospital. Through the QDI, we began our journey to positively transform care of the dying. Our first specific action was to design and implement a “Comfort Measures Strategy” across the hospital. In our search for an evidence-based approach to form the foundation of our change, we learned about the CARES tool and had the wonderful fortune to join forces with Bonnie.

By profession, I am a specialized oncology nurse and have been actively involved in cancer care for over 20 years, fulfilling various roles, including frontline nurse and leadership roles such as educator, professional leader, advanced practice nurse, and now director. These roles have enabled me to work in different settings, including the hospital, ambulatory care, and the community. This has further enhanced my understanding of end-of-life care, the diversity of patient and family needs, and the system barriers we face. I am so grateful for the privilege of living my passion as a nurse. Being present with individuals and their families through their personal health journeys has changed me and caused me to continuously reflect on what I believe and what I know. It has challenged me to live my own life differently, and to strive to find ways to improve the experience of health care from the perspectives of those we care for.

End of life is an inevitable point in the journey for all of us as human beings. And yet it remains an aspect of care that is challenging, elusive, and often silent. I am keenly aware that I bring to my nursing role all my past experiences caring for those who have died, and my own personal story. In my life, I have been significantly impacted through the deaths of those whom I love: my father, uncles, mother-in-law, and father-in-law. Each of their journeys was very different, and each revealed new insights and learning that have been woven into my life and have further driven my commitment to influence change.

As a daughter, I sat silently by the side of my father in an intensive care unit, after having his ventilator removed, watching his erratic breathing, waiting and wondering if each breath would be his last. I know how it feels to wait, to feel pain and sadness, to not know when it will come to an end, to hope for death and not want it, all at the same time. I know that when it is said that there is “nothing more that can be done,” we have limited our meaning of caring. There is so much more that can be done. We must recognize that caring in itself provides comfort and hope, and often the greatest gifts are the simplest gestures that are long remembered.

Tracey Das Gupta
My first exposure to caring for individuals who were facing death and their family members was as a new clinical nurse specialist in the mid-1970s. Oncology was just emerging as a specialty, and a large majority of those who were diagnosed with cancer died following rather arduous courses of therapy fraught with numerous side-effect management issues. This was before the advent of effective antiemetic therapies and other supportive care medications. Death was not often discussed openly, and palliative care as a philosophy had not yet entered the realm of clinical practice in our environment.

I was invited as a nursing practice consultant by the oncology team, to help the staff nurses cope with the challenges they were feeling as they cared for individuals who were dying on their unit. The nurses talked of challenges in having conversations, feeling tensions between quality-of-life and quantity-of-life goals for care, dealing with the myriad side effects the dying were experiencing, and handling the various wishes of everyone involved in the situation. They found it particularly difficult when the dying and their family members did not agree on a specific course of action or plan of care. At the time, one of the biggest issues was having an open conversation about DNR orders—there was no precedent for having this type of conversation or for coming to consensus as a team about what was to be done. Frequently, patients were not informed clearly about their diagnosis, let alone their prognosis; and the idea of actually consulting the patient about his or her wishes was not really considered. On reflection, it was a challenging time.

But for me, this was the beginning and it has been a long but rewarding journey since then. Over the years, I have had the opportunity to learn about palliative and end-of-life care, its philosophy and approach, and see the evidence for the field grow. I have had the chance to work closely with Canadian leaders in this field, to drive policy and program change, and to engage in the education of nurses about end-of-life care. It has been wonderful to participate in the introduction and feel part of the growth of the field over the years. I was thrilled recently to see that it is now acknowledged as a clinical specialty in Canada, and access to palliative care service is now stated as a standard of quality patient care and a hallmark of a high-performing health system.

I saw evidence that the field had grown when my own father died of cancer. He was informed of his diagnosis and prognosis and given choices about what he wanted to do. The actions taken by the health care team members that allowed him to spend quality time at home were so meaningful. His side effects were managed according to his wishes and the current state of knowledge about them. And my mother and the family members were included in the dialogue and decision making with him. The experience also left me with a clear picture of the difference between being a health professional in the field, when you think you have command and
control, and suddenly being thrust into the reality of being a daughter and losing a loved one. Without a doubt, the conversations the staff members had with us as family members, the openness of their support, and the way I observed how they cared for Dad made all the difference in my experience then and my remembrances of that difficult time.

*Margaret Fitch*
PART I

Care for the Dying
CHAPTER 1

Introduction to the CARES Tool

In 2012, a very skilled and respected oncologist, Dr. Chatchada Karanes, MD, sought my assistance as a palliative care nurse practitioner (NP) to help a 20-year-old male and his family through the dying process. This was not a routine request at the 300-bed cancer research facility where I worked, as most palliative care consults were strictly for pain management. The need and perceived value of palliative care consults were in their infancy, and end-of-life (EOL) consults were extremely rare. Resistance to a change in culture that incorporates palliative care was not unique to my hospital as they maintained the traditional curative focus held nationally in the United States.

Death remained an unacceptable outcome, an admission of failure, and a tragic response. Only a few physicians were beginning to view death as a possible consequence of a disease process to be supported and achieved peacefully after curative treatment was no longer an option and life-prolonging measures were deemed futile. Death in a cancer facility was just beginning to be viewed as a part of life and not exclusively as a failure.

The exceptional reputation of Dr. Karanes made her request all the more flattering, and I was genuinely impressed by her acceptance of the inevitable death of this young man under her care and her desire for his death to be as compassionate and as peaceful as possible. She welcomed my assistance to address his final stage of life and viewed EOL care as important as any other acute care procedure. I was grateful that the message of support and desire to assist in providing personalized and family-specific symptom management was being heard.
STEVEN’S STORY

The young man I was asked to see was diagnosed with acute lymphocytic leukemia and had undergone a bone marrow transplant 3 months ago. He developed an all too common complication of this treatment called graft-versus-host disease. This often-aggressive disease process was attacking his lungs. The leukemia was in remission, but the cost was a progressive and irreversible loss of lung function. This otherwise healthy young man was now slowly suffocating. Dr. Karanes asked me to provide whatever comfort I could for this actively dying young man and his family and not allow them to suffer.

In the role of a pain and palliative care NP, providing EOL care for individuals and their families was an important aspect of the services provided by the palliative care team. This role should not be exclusive to palliative care NPs as they continue to be the primary caregivers and are in a position to make an enormous impact on the lives of the dying and on a grieving family. It requires very little technical skill. The needed care is so basic, it is often overlooked or deemed unimportant. How could just being present and listening, offering a cup of tea to a family member, or applying a warm washcloth to the forehead of someone who is dying make any difference? It is my hope the readers of this book will find that the nurse’s acts of compassion and humanity will provide a huge difference. The specific act is often forgotten by the family member, but the implied meaning is retained. Yes, the washcloth or a cup of tea is insignificant, but the meaning behind them demonstrates respect, a desire to comfort, an acknowledgment of the value of the individual, and a sense of compassion that will positively support the grieving family members. If the memory of a loved one’s death is perceived as loving, calm, and supportive because of a nurse’s compassionate actions, the grieving process can be greatly assisted. This additional support will be invaluable for years to come as the family members struggle to find peace and acceptance of their loss. If the memory of a loved one’s death is filled with emotional pain, abandonment, and doubt, grieving can actually be intensified. This emotional trauma was identified as a contributing factor for the development of posttraumatic stress for one out of three family members that experience a perceived unsupported death (Ferrell & Coyle, 2010). The emotional trauma will impact that family member for the rest of his or her life and could result in the development of multiple psychiatric and socially dysfunctional behaviors.

Numerous terminally ill individuals and their families have expressed concerns about the dying process. The fear of pain and suffering is what frightened these individuals the most. Often, death itself was not the focus of their fears as much as how they would die. It is the “how” that remains...
The name of the young man was Steven. Soon after the consult request, I visited Steven and assessed how he was progressing. On arrival to his unit, I encountered three very anxious nurses and Nicole, a very caring and experienced social worker, trying to help. The nurses informed me that Steven was actively dying. My heart ached when I first met Steven. He was an emaciated, pale, and diaphoretic young man who appeared five times his age. His bald head and withered body were positioned upright on pillows. His mother was sitting on a chair next to his bed rubbing his arm with a gloved hand. She was gowned and gloved, just like the protective isolation sign instructed. Her green eyes were now red and swollen as her tears continued to flow into her white cotton mask. Steven had the same green eyes but his were open wide as he stared blankly at the ceiling. His respirations were agonal, coming at irregular intervals as his shoulders and upper chest heaved in a spasm-like motion with each breath. His pressurized oxygen mask system (BiPAP) hissed in its effort to force oxygen into Steven’s rigid lungs.

A middle-aged man with a heavily wrinkled yellow isolation gown approached the health care providers from a corner chair where he sat away from Steven’s bed. Everyone introduced themselves and I found out that the gentleman was Steven’s father. He looked exhausted and his voice trembled when he spoke as he struggled to maintain emotional control. The first question he asked me was, “Do you think he is suffering?”

I found many nurses hesitate to answer this commonly asked question. Nursing schools do not routinely prepare nurses to interact with the dying and their families, nor do they provide an emphasis on the need to communicate effectively. I realized how badly the nurses wanted to help, and how unprepared they were. Based on this observation and the experience with Steven, I planned to develop a teaching tool that could help nurses provide compassionate evidence-based care for the dying in the form of a quick reference guide.

I designed the tool to draw on the scholarly works of such knowledgeable experts in the field of palliative care as Betty Ferrell, RN, PhD, MA, FAAN, FPCN; Christine Puchalski, MD; Ira Byock, MD; Timothy Quill,
MD; Nessa Coyle, PhD, APRN, FAAN; and Elaine Wittenberg-Lyles, PhD, and wanted to instill a new respect for the skills required to effectively care for the dying by using an acronym format to encourage an association with other acronym-based programs such as BCLS (basic cardiac life support) and ACLS (advanced cardiac life support).

I decided to do a literature review and identify the most frequently addressed symptom management needs of the dying. The review indicated pain, respiratory distress, delirium, and emotional and spiritual distress to be the most common. The literature review also identified the need for self-care for health care providers caring for the dying.

I consolidated the five most common EOL care needs into a reference guide organized by the acronym CARES.

■ The “C” was selected to represent the need for comfort. This included both pain management and general comfort measures.
■ The “A” was selected to represent measures to address airway management. It involved the need to treat respiratory distress, provide secretion control, and make suggestions for educating family members on the breathing changes commonly seen with the dying.
■ The “R” was used to designate the restlessness commonly observed with the dying; more accurately termed delirium.
■ The “E” was selected to represent the emotional issues common to the dying and their families. Spirituality was included in this section to allow for a more holistic focus for the kind of support commonly required.
■ The “S” addressed the newest focus of concern when caring for the dying: self-care, to address the impact death can have on the caregiver.

The CARES tool was designed to address EOL care knowledge deficits and assist the bedside nurse to more fully understand the unique care required during the dying process. It encourages nurses to act as advocates for dying individuals and their families, and to tailor their care to their specific needs (see Exhibits 1.1–1.5).

The CARES tool was designed to help nurses in situations similar to the one under current discussion about Steven. Without training and experience, a nurse placed in this position would be challenged to provide the kind of physical and emotional support needed to answer questions about suffering, and assist an individual, such as Steven, to die in comfort.

The needs of Steven and his family are extensive. There is much that can be done to make Steven’s death a loving and peaceful experience for him, his family, and the nursing staff caring for him. Education and experience help nurses to better understand the needs of the dying. Training is essential for nurses to provide the unique care that is required. The CARES tool attempts to summarize this care and encourages nurses to take on the much needed role of advocate. Nurses are in a unique position to improve the quality of care provided for all dying individuals by
EXHIBIT 1.1 Comfort section of the CARES tool.

Comfort
You must act as an advocate for your patient to control his or her pain. Pain control is an essential need for all dying patients.

• The route of the medication determines time to maximum effect:
  – IV peak effect is 15 minutes → Orally in 60 minutes
  – Sub-q in 30 minutes → Transdermal 6–8 hours

• Terminal pain/pain during dying is best managed by around-the-clock, scheduled, or a continuous infusion of opioid (such as from a PCA pump) and additional doses (boluses) given as needed for breakthrough pain.

• There is no maximum dose of opioids for pain control.

• Nurses are often frightened that the opioid they give a patient will cause him or her to die prematurely.
  – There will always be a last dose when caring for a dying patient. Keep in mind the legal and ethical concepts of intent.
  – The patient is dying because of his or her disease process, not the opioid.

• Adjustments in dosage or type of opioid may be required in the presence of renal failure, and if the pain medication does not help to control the patient’s pain.
  – Consider fentanyl if the patient has renal failure and if the patient has small seizure-like tremors (myoclonus).
  – Opioids stay in the system longer in case of renal failure. Dosage is usually smaller.
  – Consider changing the type of opiate if pain remains uncontrolled.

The focus of care for the dying patient is comfort. All unnecessary procedures, tests, and activities should be evaluated. Providing as much time for the patient and his or her family to be together should be the priority. Consider obtaining orders as appropriate for the following:

• Stop or modify vital signs
• Stop oral medications if unable to swallow and all nonessential medications
• Clarify IV options: stop or reduce
• Stop or reduce tube feedings
• Turn off monitors and alarms
• Stop or decrease labs per physician and family preference
• Discontinue isolation

You can provide the following comfort measures without an order:

• Turn and position patient only for comfort
• Modify bathing or stop per family request
• Consider reinforcing dressings only
• Provide frequent oral care
• Provide oral suctioning if family requests
• Provide temperature comfort measures such as a cool washcloth and ice packs
• Explain mottling and cyanosis as part of the dying process and not from being cold
EXHIBIT 1.2  Airway section of the CARES tool.

**Airway**

The use of supplemental oxygen during the dying process is often ineffective but may help to minimize the family’s fears of their loved one suffering. Review goals of care established by the patient and family for supplemental O₂.

- Consider use of a fan
- Provide nasal cannula per MD orders
- Reposition patient as needed

The dying process results in irregular breathing with periods of apnea. Secretions often pool in the back of the patient’s throat resulting in loud congestive sounds. Patients can become restless and anxious. Consider obtaining orders for:

- Glycopyrrolate, scopolamine patch, or atropine 1% ophthalmic solution
- Morphine IV or Sub-q: The patient is dying and will stop breathing due to his or her disease and the dying process, and not from receiving morphine
- Consider using antianxiety agents and/or antipsychotics

Provide family education as needed; some common issues to address are:

- Breathing patterns of the dying. Breathing becomes progressively irregular, shallow, and slowed. Episodes of apnea will extend. This is all from brain stem activity. It is involuntary and the patient is not suffering.
- Emphasize the calming effects of touch and talking to the patient

EXHIBIT 1.3  Restlessness and delirium section of the CARES tool.

**Restlessness and Delirium**

The restlessness that commonly occurs during the dying process is also called terminal or agitated delirium. It can also result from pain, bladder distention, or stool impaction. The patient must be protected from injury and the family needs to be supported. Consider the following:

- Give a trial dose of opioids to rule out pain
- Assess for bladder distention and insert indwelling catheter if needed
- Assess for impaction if appropriate
- Consider antipsychotics: haloperidol or chlorpromazine
- Consider benzodiazepines: lorazepam or midazolam
- Maintain calm environment
- Minimize bright lights
- Play patient’s favorite music
- Talk softly to patient; maintain use of touch and presence
- Comfort patient by saying: “You are safe. We are with you. We love you.”
- Consider aromatherapy

Unfinished business may cause restlessness. Discuss with the family possible causes of anxiety.

- Review with the family the importance of saying good-bye and giving permission to stop fighting
- Question family about an important family event or anniversary

Educate the family on:

- Patient lacking awareness of behavior
- Possibility of being peacefully confused
EXHIBIT 1.4 Emotional and spiritual support section of the CARES tool.

Emotional and Spiritual Support

Providing emotional, spiritual, psychosocial, and cultural support to the patient and family allows us to care for the soul. This is the very foundation of caring for the dying. It is important to know your resources:

• Notify supportive care medicine team members for assistance. Be specific if resources are for patient, staff, or both.
• Always work to retain the patient’s dignity and feelings of value.
• Remember every family is unique and grieves differently. Good communication is essential:
  – Ensure communication exists with the family and all disciplines.
  – Take your cues from the family. Do not assume you know what they are thinking or feeling
  – Clarify how much the family wants to know
  – Clarify goals of care
  – Clarify privacy needs
• Just be with patient and family and sit in silence
• Work with family to provide favorite activities, smells, sounds, etc.
• Support rituals and assist with obtaining desired clergy or equipment.

Other activities and methods of support to consider:

• Your humanity is needed the most now. Always be available. Your very presence is reassuring to the family.
• The family is an important part of your patient care and becomes your focus as the patient becomes more unresponsive.
  – Be sure families are getting rest and breaks
  – Provide coffee, water, etc.
  – Continue to be available to answer questions
  – You cannot take away their pain; acknowledge their emotion and be present
• Play a patient’s favorite music.
• Position the bed to see out a window.
• Encourage the family to provide patient’s favorite hat, clothing, etc.
• Lower or mute lighting.
• Consider bringing in favorite pet.

EXHIBIT 1.5 Self-care section of the CARES tool.

Self-Care

The health care providers must allow themselves to be human and expect some personal emotional response to the death of their patient and for the grieving family. Palliative/supportive services are available to staff. Often, a review and debriefing can assist with professional grieving and promote emotional health by:

• Recognizing the stressful event and thanking supportive team members
• Reviewing what went well and what challenges need to be addressed
• Sharing comments of the bereaved family
• Addressing moral distress issues
• Expressing issues of death anxiety and obtaining support
• Exploring challenges and privileges of assisting a fellow human being through the dying process
• Acknowledging the spiritual impact of witnessing death
• Exploring how your care made a difference to the grieving family
• Reviewing effective communication techniques, available resources, and support
championing the delivery of evidence-based compassionate EOL care as a standard of practice.

This book attempts to supply additional information and insight into the important role nurses need to embrace when caring for the dying. It provides information about the CARES tool and offers further rationale to explain the prompts and suggestions furnished in the tool for consideration.

The CARES tool emphasizes:

1. Care of dying individuals must include methods to address their specific needs and those of their families.
2. All dying individuals and their families have unique methods of grieving, communication, and holistic supportive needs.
3. The dying person and his or her family must be treated as one unit.
4. The need for the nurse to develop good teaching skills and effective communication techniques to provide individualized, empathetic, and compassionate holistic care.
5. The need for nurses to be advocates for individuals under their care through clear communication of mutually established goals, anticipation of necessary medications, equipment, and treatment adjustments, and holistically supporting a peaceful death.
6. The need for nurses to embrace the importance of their humanity, compassion, empathy, ability to actively listen, and to be therapeutically present.
7. The importance of self-care, professional grieving, and the need to acknowledge and address the impact caring for the dying has on us as human beings.

Basic tools and rationale on how to achieve the goals addressed in the CARES tool are provided throughout the chapters of this book.

The CARES tool is supported by extensive peer-reviewed literature on care of the dying. The volumes of evidence-based information can be overwhelming and often intimidating when a bedside nurse just wants to know what to do next. The CARES tool is based on the most common needs of the dying and their families identified in the literature and arranged in an acronym format. The busy nurse can quickly review what still needs to be addressed and what they can request or order within their scope of practice. A strong background based in education and training for the dying is essential for the most effective use of the CARES tool.

It is also essential that a nurse caring for a dying individual is aware of his or her own cultural and spiritual beliefs, and concerns about death. If a fear or concern about some aspect of the dying process exists, it is common for the nurse to withdraw in an unconscious effort for self-protection. Nurses must become aware of their feelings and reactions toward death.
Nurses cannot help but bring their uncertainties or cultural bias to the bedside, but they can be tempered if one is self-aware.

A positive focus on caring for the dying must also be noted as many nurses and health care professionals enjoy this challenging discipline of health care. Hospice nurses continue to demonstrate low job turnover rates often recounting amazement about how much they receive personally with each caring experience. Hospice nurses express an awareness of the opportunity to rework personal losses, an ability to more easily dismiss inconveniences and irritations, an acute awareness of the beauty that exists around them, and a deep appreciation of life because of their interactions with the terminally ill.

The dying and their families have so much they can teach us, and nurses have so much they can give. When a balance is achieved, the interaction can be deeply spiritual. Nurses are challenged by the dying to help them feel respected, valued, supported, and listened to in the fast-paced computerized hospital setting. Acting in this compassionate and humanistic manner will help keep many nurses grounded and focused on what is really important. They will be reminded that the greatest gifts they can provide the dying and their families are their willingness to actively listen, educate, reassure, empathize, compassionately communicate and, above all, embrace the use of their humanity.

The needs of the dying are the reasons many individuals become nurses and the care they require mirrors what nurses identify as what differentiates them from any other health care professional. It is time nurses embrace their role as advocates and honor the unique services only they can provide. Nurses are trained to care holistically and advocating the needs of persons under their care is essential to this role.

REFERENCES
