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The clinical treatments described and recommended in this publication are based on research and consultation with nursing, medical, and legal authorities. To the best of our knowledge, these procedures reflect currently accepted practice. Nevertheless, they can't be considered absolute and universal recommendations. For individual applications, all recommendations must be considered in light of the patient's clinical condition and, before administration of new or infrequently used drugs, in light of the latest package insert information. The authors and publisher disclaim any responsibility for any adverse effects resulting from the suggested procedures, from any undetected errors, or from the reader's misunderstanding of the text.

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JOY UFEMA has always been ahead of her time. In 1987, when she began writing for Nursing, she had already been working in hospice care for 14 years. By sharing her experiences with nurses, she taught us how we could better communicate with and comfort dying patients. In those days, her honest, open approach was revolutionary.

The article she published in Nursing87 was called “How to Talk to Dying Patients.” It starts with a nurse speaking these simple words: “I’m afraid I’ll say the wrong thing.” The feeling, then and now, is universal — we’ve all been there. Even after years of experience, many nurses hesitate to discuss death and dying with patients. Yet, more than anything, we want to be the best nurses we can be for our patients and their families at this important time. Joy’s advice — be kind, be real, be honest, be yourself — struck a chord with readers hungry for guidance and support.

So the next year, we launched Joy’s column, Insights on Death & Dying, and it has appeared monthly ever since. Year after year, it has remained one of our most highly read columns. It has “legs” because Joy tells the story of her experiences in a way any nurse can relate to. Setting the scene with dialogue and intimate details, she draws you to the bedside with her. You are there when a dying patient asks Joy the tough questions. You are there as she responds. That’s what makes Joy’s writing powerful, memorable, and a great learning experience.
Caring for dying patients is like nothing else you do as a nurse. You can’t scan the Internet for a formula or algorithm or nursing diagnosis to guide your decisions or help you choose the “right” words. Each patient has different needs, and each of us brings something different to the bedside. Joy lets us know when we need to get rid of our own baggage to do a better job for our patients.

Joy has shared her most moving experiences with Nursing’s readers for almost 20 years, and we regularly hear from grateful nurses who have been helped by her work. Now we’re proud to bring you this collection of her favorite columns.

Whether or not you’re already acquainted with Joy’s work, you’re in for a treat. Reading Joy’s columns is like talking to a friend. She’s kind, she’s real, and she’s always herself.

Cheryl L. Mee, RN, BC, CMSRN, MSN
Editor-In-Chief, Nursing2006
Program Director, Nursing2006 Symposium
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IT WAS ONE of those delicious summer days made all the more intoxicating because I was 10 years old and had a woodshed of raw material at my feet.

“Hey, look at this old box,” I said excitedly to my chums. “It looks like a strongbox for a gold shipment! I’ve got an idea! Let’s build a stagecoach!”

Thirty years later I was sitting in front of the Director of Nurses at Harrisburg Hospital relating how I found that my dying patients didn’t require sleeping pills if I spent some time asking if they would like to share their feelings. “I’ve got an idea! I’ve been attending all these Kübler-Ross seminars, so let’s create a position of Nurse-Specialist in Death and Dying!”

A decade later, I had received some gracious notoriety for the experiences gained from that idea. Nursing journal asked that I review and write some articles on death and dying.

Feeling emboldened by those successes, I called Nursing and said, “I’ve got an idea! Perhaps I could share a portion of my knowledge in the format of a question-and-response column!”

That was 1986, and I’m honored that my column has appeared in many, many issues since.

Rather than save the entire magazine I began cutting out those monthly columns, with their beautiful illustrations, and placing them in plastic sleeves within a three-ring binder. Amazed by the plethora and diversity of information that had accumulated over the years, I again telephoned Nursing and said, “I’ve got an idea! Let’s make a little book of my favorite columns!”
And that is how you came to have this “idea” in your hands at this moment.

But perhaps why is more important.

My intention in compiling this assemblage is to offer the reader an opportunity to revisit some of those patients who had an impact on my practice. Those newly introduced to my column may possibly discover a new or different approach in helping the distressed patient and his family.

It is also my desire to impart a bit of practicality to help the nurse feel more comfortable in applying some of the recommendations. I’m not an expert. I have simply chosen to have thousands of experiences with death. Each patient was a teacher, good or bad, in his own right. I want to pass down what I have learned before I “pass on.”

Hopefully, these stories will prove beneficial in your professional or personal life. The chapter on “Advocating for patients and families” may be just the key you need when seeking inspiration to take a stand on truth-telling. “Mastering patient management” could provide a few “tricks” to help your father-in-law with severe shortness of breath. I’m emphatic about each of us expressing our own authenticity. “Taking care of yourself” may inspire you to play as hard as you work.

It all comes down to acknowledging that it matters more how we die than that we die. And I believe strongly that we die the way we live. Someone who has been a man of few words all his life will not suddenly become loquacious when told he has inoperable pancreatic cancer. How to help him express those feelings? What do you say when he says, “Tell me the truth, nurse, am I going to die?” And even though each of us will die, it would be trite to say so at that tender moment.

In the rich writing of Larry McMurtry’s Comanche Moon, we travel into south Texas in the mid 1860s. Two life-long pards, Augustus McCray and Woodrow Cull, have been made Captains of the Rangers. Fighting to tame the West, they have seen an inordinate amount of violence and death. Through it
all, their friendship is forged as they’ve had to protect the men under their command as well as each other.

McCray is seated by the bed of his mortally ill young wife. The hotel room is dirty and sparsely furnished. He gently wipes the sick woman’s face with a damp handkerchief.

Captain Cull knocks softly, then tells McCray they’ve been beckoned by the Governor.

“Woodrow, I can’t leave to see no Governor right now. I’m helpin’ Nellie die.”

Isn’t it fortunate that in 2005 we have so much more to offer our dying patients than a cold cloth?

But words are equally important in that repertory of analgesics, antiemetics, and anxiolytics.

Take these words; make them yours, if you so choose. But always find it a noble thing to sit and “help Nellie die.”

Joy Ufema, RN, MS
To Rose Foltz,
whose kindness and skill at wordsmithing
make me look good.

I want to offer a special recognition
to the thousands of dear patients and their families
who permitted me to enter their lives during difficult days.
It is from them that these stories come to teach us all
the arte and crafte of dying.

And
to Linda Lighty,
who patiently typed many columns over the years
on those days when I returned home weary and woeful.
Thank you for always giving me tea by the fire.
Overview
Brief history of end-of-life care

The wife of a rich businessman has contracted tuberculosis. The doctors have pronounced her condition hopeless. The moment has come when she has to be told. There is no question of avoiding it, if only to allow her to make her “final arrangements.” But the husband refuses “to tell her about her condition” because, he says, “it would kill her...no matter what happens, it is not I who will tell her.” The mother of the dying woman is also reluctant. As for the dying woman, she talks about nothing but new treatments; she seems to be clinging to life, and everyone is afraid of her reaction. However, something has to be done. Finally, the family enlists an old cousin, a poor relation, a mercenary person who throws herself into the task. “Sitting beside the sick woman, she attempts by a skillfully maneuvered conversation to prepare her for the idea of death.” But the sick woman suddenly interrupts her, saying, “Ah, my dear! Don’t try to prepare me. Don’t treat me like a child. I know everything. I know that I haven’t much longer to live.”

Fast-forward from this 1859 excerpt from Tolstoy’s “Three Deaths” cited in Philippe Ariès’s tome The Hour of Our Death (Knopf, 1981) to one from A Few Months to Live: Different Paths to Life’s End, a publication by Staton, Shuy, and Byock (Georgetown University Press, 2001):

“My doctor seemed to want to be encouraging as opposed to discouraging. I think maybe he personally made the decision about whether I could handle the [knowledge]. A lot of that is a blur with what I was told. I know that I remember my husband coming in, and he was in so much despair. I was asking him to talk to me and tell me and that’s when he started crying and saying, “I don’t want to lose you. I don’t know if I can handle this.”

In 1973 at the Royal Victoria Hospital in Montreal, Dr. Bal Mount and colleagues conducted a study in which physicians were found to be reluctant to be candid about death and dying, yet the patients wanted honest, open discussion.
As reflected in the above pieces of literature and reinforced by the Royal Victoria study, death is seen as the enemy except by those doing the dying.

We used to see death as a natural consequence of life. In fact, by the 1500s the *Ars Moriendi* tradition was prevalent. Translated as “the arte and crafte of dying,” these guidebooks described rituals that were to be performed as part of the deathbed scene.

The “main character” wasn’t the dying man himself, but the priest. It was he who gave guidance in proper leave-taking, the giving away of chattel, and the dutiful goodbye. The patient then assumed a reclining position and waited for death to arrive.

By the end of World War II however, the bedroom was replaced by the hospital ward and, logically, the priest by the physician. With the more technical advances came a new concept: the failed machine.

The personal relationship between doctor and patient became altered. This depersonalization was tolerable if the treatments resulted in cure. But it wasn’t as easily endured if death was a more likely prospect.

So we now have death = failure = denial.

Fortunately, the early 1960s saw the prevalence of writings, lectures, and seminars on death and dying.

Most eminent at the time was the ground-breaking work of Elisabeth Kübler-Ross, the Swiss psychiatrist who wrote *On Death and Dying*. Her observations, after interviewing hundreds of terminally ill patients, proposed the five stages commonly experienced: Denial, Anger, Bargaining, Depression and, finally, Acceptance.

This instant best-seller brought death “out of the closet,” although some thanatologists felt it was a cookbook “recipe” that labeled patients. I acknowledge the value of Dr. Kübler-Ross’s contribution but recall shuddering at seeing a freshly scrubbed student nurse, clutching a copy of the book, striding determinedly down the hall, seeking an unsuspecting patient.
upon whom to affix one of the five steps in the complex journey of leaving the planet Earth.

The first free-standing, bricks-and-mortar hospice was built in New Haven, Connecticut, in 1974. It was a prototype based on Saint Christopher’s Hospice in Sydenham, outside of London. Its founder, Dame Cicely Saunders, a social worker turned nurse turned physician, summed up the philosophy of palliative care by stating, “The patient should be in the center.”

Does that wisdom still hold true in how end-of-life care is practiced today?

**The current thinking**

There’s an ancient Persian legend that tells of the servant who burst into his master’s quarters pleading for a fast horse to flee to Samarra. He explained that he had just met Death while walking in the marketplace in Baghdad. The master granted the servant’s request. Later, while walking in the marketplace the master met Death sitting near a tree. “Why did you frighten my servant?” inquired the master. Death replied, “I did not wish to frighten him. I was a bit surprised to see him here for I have an appointment with him later tonight in Samarra.”

And so, no matter how fast the horse, each of us has an appointment with Death.

The problem is, we don’t really believe that we will die. If we did, we certainly would live our lives differently.

Contributing to this denial is the influence of the media. Spend an hour or two watching such television shows as “ER” and “House.” The prevailing message is when it comes to saving a life, the end always justifies the means. And even if Death is the victor, the fight was worth the price of dignity!

Even in the midst of futility lies a sense of entitlement to have “everything” done that can be done. And even if the unfortunate patient ends up being in a persistent vegetative state, like 25,000 today in this country, he can be fed through tubes and pee through tubes...but, hey! He didn’t die!
Years ago, if a man didn’t come in from the fields to eat dinner, his son or daughter was sent to fetch him. There the farmer lay, dead from a myocardial infarction, face down in the sweet earth he tenderly plowed. The team of horses stood quietly, waiting for his familiar commands. Later, they would be asked to pull the wagon bearing the farmer’s coffin to the family cemetery. It was all so lovingly natural.

Now, I find the modern hospital death obscene. I’m offended by the absence of decency that every human deserves. “You wanted us to do everything we could! Now look what we’ve got!” I want to shout.

Don’t people know there are worse things than death? This is the time to utilize one of the 2,400 hospice home care programs in the nation. Most provide an excellent service at helping families grant the requests of patients to die at home.

The problem is that 37% of patients die within 7 days of admission. This hardly affords time for the hospice team to get to know the patient and family. It’s difficult to advocate for how the patient defines a meaningful death when he’s comatose during the admission process.

If the physician feels the time to discuss palliative care has arrived, and if she’s comfortable in initiating the conversation, the patient might thwart those efforts by saying, “But Doctor, I’m not ready for hospice.” Which really means, “I’m not ready to die. Isn’t there something more you can do?”

One hundred years ago, the town doctor sat on an old rocking chair beside the tiny bed on which a feverish child lay. He gave laudanum and cooling baths. As the terrified parents stood in the lamplight, surely they wished for the physician to “do more.” But he had nothing more, and the child died.

Today, not only do we have more, we may have too much in our arsenal in the war on death. A 90-year-old lady is taken from the nursing home to the hospital, where aspiration pneumonia is easily diagnosed. The poor dear is frail and has lived...
long enough to develop congestive heart failure and some mild dementia.

Insertion of a feeding tube is recommended. The daughter is hesitant until the attending physician defines the procedure as “minor” and then adds, “You wouldn’t want your mother to starve, now, would you?”

The social worker or nurse offers the option of “just keeping mother comfortable.” There is no advance directive because we don’t really believe we’re going to die, and now the daughter is feeling confused and fearful.

“I don’t want to be responsible for killing her.”

I’m fairly certain that aspiration pneumonia occurred 100 years ago. Because we didn’t have feeding tubes then, none were offered. The patient knew he was going to die, as did his family and physician.

This focus in the 21st Century of keeping the organism alive is becoming distasteful.

Because death is the only sure thing we know will happen one day, why aren’t we preparing ourselves for the event?

“If I’d known I was going to live this long, I’d have taken better care of myself.”

I fear for our society in general and for healthcare providers in particular.

Betty Ferrell conducted a survey at the City of Hope Medical Center. Of the nurses polled, 66% rated care of the dying better in 2000 than 5 years earlier. But the survey revealed that, overall, nurses felt their basic education to be inadequate in preparing for end-of-life care. They’re distressed by patients experiencing unrelieved pain and symptoms.

These feelings are further substantiated in the audiences throughout the country to whom I speak on my lecture circuit. Nurses are frustrated by not knowing what to say and fear “saying the wrong thing.” They’re confused and exhausted by providing care in the midst of futility. They feel guilty for inflicting fruitless treatments, even when the patient himself re-
quests it. They're finding it difficult to receive intrinsic rewards.

**End-of-life care guidelines**

**For the patient**
Just as a hand massaged in an uncomfortable position remains uncomfortable after the massage, a patient lying in sweat-soaked linens while being counseled about dying isn't benefiting from the counsel.

The most important thing for a nurse to do for a dying patient is to be his nurse! By that I mean wash his achy body and sweaty hair, massage his back and smooth his sheets, give superb and thorough mouth care, and then sit by his side.

We know patients fear pain and abandonment, yet we could do so much more in both areas.

The following five points identified as equating quality of care at the end of life may provide guidance.

#1 To receive adequate pain and symptom control
It’s obvious if the patient is an “8” on the pain scale of 0 to 10 that he won’t and can’t fully enjoy a visit from his exuberant, loquacious 5-year-old granddaughter.

Nor can the young mother with ovarian cancer suffering with intractable nausea from a partial bowel obstruction speak of her fears of leaving twin sons.

We owe the terminally ill person the commitment of working indefatigably to provide aggressive palliative care.

There’s a difference between the biology of disease and the experience of illness. When the patient is upset, he has more symptoms. Therefore, the logical thing to do is validate his feelings and concerns.

The French philosopher Simone Weil once said that the only suitable question to ask another human being was “What are you going through?” A gentle touch on the dying person’s
shoulder and a sincere, “I can’t imagine how difficult this must be for you,” tells the patient you are not only listening but are actually hearing his concerns.

The chapter titled “Mastering patient management” offers specifics on treating dyspnea, constipation, bone pain, and much more.

#2 To avoid the inappropriate prolongation of life
I stood beside the oncologist, nudging him gently toward the head of the bed. The patient was a 72-year-old gentleman, retired from teaching at the local junior high school. The cancer of his jaw and chin had been particularly menacing. Now, with further treatment not a favorable option, hospice was to be offered.

“The chemo isn’t really working,” the doctor explained.

The patient nodded almost imperceptibly.

Breaking the uncomfortable silence, the doctor blurted out, “But we could give you more, if you want.”

Mr. Shaeffer didn’t want.

He might have wanted his physician to be replaced by Richard Parker, who might have explained the end of life as he wrote in the January 2002 Annals of Internal Medicine: “I liken the process to a clock no longer wound every day that gradually runs out of energy. When the clock runs down, all the parts stop.”

It’s important to the dying person that he not be kept sicker, longer. Prolonging life simply to stave off death one more day wastes precious time during which the patient’s energy and the opportunity to come to terms with himself can be lost.

These cherished days can otherwise be spent with loving family and friends, like a king leaving a banquet table.

Diagnosed with a deadly form of leukemia, Stuart Alsop quipped, “Just as a sleepy man must lie down to sleep so must a dying man lie down to die.”
#3 To feel a sense of control
Derek Doyle, my hero and esteemed palliative care physician from Edinburgh, Scotland, tells of the terminally ill patient hesitant to be admitted to the hospice. She asks, “Do I have to eat?”

The soft response, “No.”
“Do I have to wash?”
Again, “No.”
“May I sleep as long as I want?”
“Yes.”

Her cancer was out of control. Her emotions were barely under control. Now, she has this opportunity to regain a semblance of control in her life, something each of us takes for granted. The moment we get out of bed in the morning, we take control of the events of the day. We eat anything we want for breakfast and it stays down. We run upstairs to retrieve a sweater and we aren’t dropped to our knees by pain. Our body is still our servant.

But the body of Dr. Doyle’s patient has betrayed her, and she seeks control in the simplest ways because to ask for more is risky.

I recall caring for a lovely lady with a difficult, aloof husband. When she had her mastectomy, at first he was fairly attentive, but as she regained a modicum of strength he withdrew. Even when lung and bone metastasis forced her to take to her bed, he would immediately retreat after complying with a request.

While visiting, I observed her ask her husband to bring her some fresh water.

“And, John, make sure you put two or three ice cubes in, not too many.”
Silence from the kitchen.
“And, John, would you please put it in the blue glass?”
She hadn’t had much control in the marriage, but her terminal condition provided both the bravery and the permission to make requests.
She didn’t push it by asking John to give her a backrub.

It’s imperative to be acutely aware of ways to give the patient a sense of control in an uncontrollable situation. Patients want to feel worthy of being served, not patronized. You wouldn’t want to attempt to provide control by saying, “Would you like your bath before or after your favorite television show?” This is a tactic useful in pediatrics, but your patient is an adult who has made major decisions for herself all her life.

It’s much more dignified to ask if she would like to be bathed and, if so, when would be best for her.

Keep in mind, she’s losing all the sunsets, all of her grandchildren, all of her music and books, all of her all.

So, when, not if, she’s pushing the call button every few minutes, she isn’t doing it to harass you. She’s simply attempting to regain some control in her world. You have control over yours. Be kind and compassionate.

#4 To relieve the personal burden on family

It’s difficult to lie around. It’s even more troublesome to always be on the receiving end of a relationship. To be lovingly cared for may be comforting; to be taken care of may be demeaning.

The hospice home care philosophy states “the patient and family is the unit of care.” Yet, we may be asking a young family member to have her first death experience be that of a beloved parent, brother, or child.

Granted, if given a choice, most people prefer to die at home, cared for by family and friends in familiar surroundings. In fact, 90% of Americans feel the family has the responsibility to provide care at the end of life.

But for the patient to see exhaustion and fear in the eyes of his caregivers can have an effect on the quality of leave-taking. Perhaps he’s a husband and father. His role had always been to protect his “girls.” Now he sees his wife and daughters struggling to keep up with the washing, the cooking, and the caring. They fall asleep after sitting down for a few minutes. This caretaker fatigue may give an unspoken message of “burden.”