



The Seven Agreements

**A Guide for Nurses and Physicians
Providing Care to the Dying**

by

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The medication suggestions in this manual are adapted from several sources named in the reference section and from a combined knowledge of many years of clinical experience providing symptom management to the dying on the part of both JoAnne Chitwood, RN and Jeffrey Melendez, M.D.

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Foreword

Some time ago I was working as a night hospitalist on the medical floor of a busy hospital. We had a strict policy that the night doctor would take care of emergencies but would not change the plan of care created by the morning doctor, who was attending to the patient.

For several nights, I was called about a patient with severe transfusion dependent myelodysplastic syndrome. The patient's hematuria was so awful that he kept clogging the Foley catheters with blood clots. For the first several nights that this happened, my response was to order a new Foley catheter each time it clogged, continue bladder irrigation, and repeat transfusions of blood and platelets.

After several nights of this, a nurse questioned how we were caring for this patient. I listened carefully to her concerns, then I went to examine the patient myself. The patient was nonverbal but visibly uncomfortable with abdominal pain on exam and had a Foley catheter bag full of blood. I did a thorough review of his chart and it didn't take long for it to become clear to me that this patient was suffering due to a terminal disease and we were just prolonging that suffering with our blood transfusions and other treatments.

I picked up the phone, even though it was the middle of the night, and had a calm and honest conversation with his daughter, who was the power of attorney for her father. I described what I saw and told the daughter that I felt her father was suffering. I recommended that all transfusions be stopped and that the patient be placed on comfort measures.

The daughter thanked me and told me that I was the only person that had actually explained to her what was happening in terms she could understand and that she was very worried about him but did not know what to do. After our phone conversation, we placed the patient on comfort care and gave him morphine for pain. He looked significantly more comfortable and relaxed.

He died before the end of my shift that night.

When I called the daughter and gave her the news, she cried with relief and thanked me over and over through her tears. She felt that someone had heard her and fought for her father's comfort instead of just seeing him as a set of medical problems to be solved.



That morning, after I gave report to the oncoming physicians, the attending physician thanked me for taking care of that very difficult case. I still remember driving home that morning and feeling a deep sense of satisfaction for taking the extra time to make a difference in that patient's life.

Many of us in health care came into this profession with the goal of healing all of our patients and eradicating disease. Many of us quickly realize, however, that caring for chronically ill patients and for patients dying of their illness is commonplace. While we still get to cure patients occasionally, our service for most patients consists of stabilizing an illness, preserving function, and, in many cases, providing palliation and comfort at the end of life.

In my story about the man with myelodysplastic syndrome, the attending physician did not accept death as an option even though he was terminally ill, so she kept transfusing him with blood products to keep him alive. In essence, the agreement she was making with the family was, "I will keep you alive no matter what the cost to you." What she was doing was prolonging suffering. For that particular patient, death was inevitable and comfort care was the most appropriate plan of care.

End-of-life care can be difficult for many providers. Healthcare workers, especially nurses and physicians who set the tone for patient care, should be able to view death and dying, not as a medical error, but as a part of life that everyone will experience. Providing effective and compassionate end-of-life care is an art involving multiple disciplines. And the provider needs to be willing to accept his or her own feelings about death and dying and to reach out for help from others with special training in the various aspects of end-of-life care.

To take care of someone during this special time of life, the plan of care must include management of the physical symptoms of a terminal illness while still being attentive to social, psychological, spiritual, and cultural matters that are also equally plaguing the patient and family as the person is dying. A palliative care worker accepts death as part of life and can discuss difficult end-of-life topics with the patient and the family while at the same time providing support, sympathy, and empathy.

For example, I once had a patient that was referred to hospice care. I could see, after reviewing the records, that this patient clearly had less than a few weeks to live due to terminal metastatic cancer. Unfortunately, however, the patient and family refused end of life care despite there being no other treatment options. They were convinced that hospice was not for them and they insisted that they would take the patient home and care for him without hospice support.



Shortly after that conversation, a hospice nurse went into the room and spent what seemed like hours with this family. The next day, the patient was discharged home from the hospital as planned and, to everyone's surprise, was admitted to hospice. The family and the patient seemed calm and at peace with their decision.

The patient died about a week later.

Later, this family approached me and told me that it was because of their conversation with that very caring hospice nurse that they signed up for hospice and they were very happy they did. They told me that during this family meeting, the hospice nurse talked openly about death and dying and about the seven agreements that the hospice team would make with them to provide comfort and care to their loved one. This very important conversation took away the family's fear of death and turned it into an opportunity for hospice to help someone who was suffering and needed help and care in order to die with dignity and comfort.

That nurse was JoAnne Chitwood, the author of this book, and the seven agreements she made with the family of that dying man are in the pages that follow.

Jeffrey Melendez, MD



Dedication

To the Team at Mat-Su Regional Hospice

**I've never seen such passion and compassion
in the face of formidable challenges.**

**You are each beacons of
light, love, and hope in our community.**



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Hospice

Holds the dignity of the patient sacred.

Offers hope and affirms life.

Surrounds the patient with a familiar environment.

Participates with the family in providing care.

Initiates and maintains pain and symptom control.

Cares for the emotional needs of the family unit.

Extends bereavement care for a year after death.





The Seven Agreements

The dying process has been with us since the beginning of time but that doesn't mean that it has been very well understood by most people, healthcare providers or not. Often, it has been shrouded in mystery and, for health care providers, carries with it a vague sense of failure and helplessness. We have been so focused on physical cure for disease that we have, more often than not, missed the richness and the opportunity for healing of the soul and spirit that is present in this last stage of a person's life.

In my thirty plus years as a hospice professional, I have seen hundreds of people go through the process of dying, sometimes with strong family and community support and sometimes not. What has been remarkable to me is to see the common threads that run through the process for everyone, no matter their diagnosis. This time period, from the time the person realizes they are terminally ill until they take their last breath, is sacred and has universal elements that transcend culture, family structure, belief system or medical model.

There are many similarities between this stage in a person's life and the one he or she experienced from conception to about a year old, just in reverse. At both of these times, changes are happening thick and fast. The baby in the womb is completely dependent on his caregivers and feels safe in his warm, dark place of rest. After birth, he needs to make eye contact with his parents and other loved ones to know that he is seen and to have his signals of discomfort responded to to know he is heard. He gradually gains mobility and becomes able to feed himself and eventually will care for his own personal needs, such as toileting and dressing. While these physical things are happening, his spirit is wide open. He feels and absorbs the emotional energy in the relationships around him. If the family system is an open and loving one, he feels safe and supported to explore and experience his world.

At life's end, the person gradually loses the abilities that were gained in that first year. Functional abilities fall away as weakness increases. The person becomes incontinent of bowel and bladder and has to wear adult diapers. The person loses his ability to speak but not his ability to hear. Although vision may or may not become dimmed, the dying person needs to be able to look into the eyes of those caring for him and know he is seen and valued.

Eventually, across the board, no matter the terminal diagnosis, the ability to swallow starts to go, causing aspiration if food and fluids are forced. He or she is taking nourishment from the inside and is unable to take it from the outside, just like a baby in the womb takes nourishment through the



umbilical cord and not through the digestive system. And, finally, when he is unable to respond or move at the very end, he needs to feel wrapped up in a cocoon of safety, compassion and love. Just like in infancy, the dying person's spirit is wide open during this last stage of life. Life review is crucial to the person's sense of purpose and completion. As a counselor friend of mine likes to say, "He is finishing well." In addition, the potential for healing in the family system is enormous. It is a time of transition and, like all times of upheaval, it feels uncomfortable and disorienting to everyone involved. It opens them up to new ways of thinking and to forgiveness of old hurts and recommitment to family values and connection.

There has never been a time in the history of humanity that it didn't "take a village" to support these important transition times in life. Healthy communities are connected and supportive communities. They rally around their families, supporting them when they need it.

Unfortunately, much of our modern society (in the U.S. at least) has abandoned the community structure that promotes and commits to involvement in each other's lives. Birth has become a sterile procedure that for many years didn't take the emotional and spiritual needs of the baby and the family into consideration at all (until birthing centers, dulas and midwives changed the story). And the hyper focus on medical intervention, no matter what cost emotionally and spiritually to the dying person, combined with our isolation from each other as a society, has done violence to the sacred tender space that is the dying process.

The hospice movement, started in the U.S. in the seventies, has dedicated itself to reversing that trend and creating a village for people to be able to sink safely into and have their needs met while they are transitioning from this life to the next. It recognizes the seven basic needs of a dying person and his or her family.

These seven needs are:

1. To understand what is happening and have hope that it has meaning and purpose
2. To be supported in practical ways
3. To have a voice and feel truly heard and respected as a whole person
4. To have pain and symptoms managed so they don't distract from the tasks the dying person must accomplish during this stage of life to "finish well"
5. To have his or her spiritual self engaged with and honored
6. To be supported in their grief over the many losses they are facing
7. To know that their health professionals are caring for themselves so they can continue to offer deeply empathetic care without the compassion-deadening effects of burnout



So, in light of these basic needs, it is from the heart of the “we will be your village” commitment that the Seven Agreements spring. These agreements change the story for the dying person and his family from one of hopelessness and fear to one of purpose, comfort and a renewed, although altered, sense of hope.

It is no light commitment to take on the responsibility of making the Seven Agreements with your dying patients. I can tell you that it will almost certainly increase your vulnerability to grief and pain. It will cause you to come face to face with your own mortality, which can be frightening. And it will also reach out depths of compassion and empathy in your heart that will spill over into your entire life and enrich it in ways you can't even imagine now.

I salute you for your courage in embarking on this journey. May you be inspired, empowered and encouraged by the information you learn here. And may the light you bring to your patients and their families illuminate your own path of service to those who need your loving care.

JoAnne Chitwood, RN





Chapter 1

I Will Help You Understand the Journey

1. I Will Help You Understand the Journey

Concepts in End of Life Care

Just the facts, please...



A woman stands at the bedside of a dying man. Her eyes fill with tears as he, her husband of 65 years, takes his last breath. She begins to speak softly to him, gently touching his hands, running her fingers over each of his, telling him how much she has loved his strong hands and how he used them to provide for her and for their family. She is saying good-bye.

She feels deep sadness, but also a strong sense of satisfaction. Everything that could have been done for her husband's comfort and for her support has been offered to her. She realizes that this transition in her life could have been much different if she hadn't had the loving support of her local hospice team. Especially her beloved nurse, who stayed with her in the long hours before her husband's death and knew just what to do to keep him comfortable.

Without the presence of knowledgeable, skilled, and dedicated end-of-life care givers, she would have been alone in a frightening and unfamiliar landscape. She would be facing profound loss

and difficult medical decisions without support or guidance.

Death comes to each one of us, someday, somehow. None of us knows when that time will come. Some of us plan for it and some of us don't. Some of us think about the implications that a terminal illness might have on our plans, hopes, dreams and relationships. Some of us prefer to live in the moment and leave those possibilities in the realm of the unknown until they actually occur.

And occur they will. More than 5 million people die each year. One in ten of those deaths is from cancer, many of the others from AIDS, chronic diseases, and other life-threatening conditions. Many are in long term care facilities. Many more are choosing to die at home surrounded by their children and grandchildren, pets, and familiar personal items. All would benefit greatly from caregivers who understand the special needs of a dying person.



Chapter 1

I Will Help You Understand the Journey



About Hospice

Hospice was a term used centuries ago to describe places of refuge along the rough, rugged paths of the Swiss Alps. In these shelters, weary and wounded travelers found rest and loving care. Although hospice today is a system of care rather than a particular place, it still provides support, respite, and relief to weary travelers: those walking the path of a terminal illness and the loved ones who suffer with them.

The focus of hospice is on the individual and the involved family rather than on the disease. It is the goal of the hospice staff to provide for the whole person, emotionally, physically, and spiritually. Care focuses on restoring dignity and a sense of personal fulfillment to the dying by allowing choices, listening, and caring.

To provide the very best care possible, a multi-disciplinary team shares the responsibilities involved in attending to the needs of hospice patients and their families. The hospice team, made up of a medical director, the patient's primary physician, nurses, social workers, pharmacists, chaplains, home care aides, volunteers, therapists, and others, meets at least every two weeks to discuss ways to best support every hospice family's needs.

Although hospice care is not for everyone (some situations and problems are more medically complicated and the patient or family may not opt for palliative care) it offers many advantages. Some of these basic components of hospice are:

- 24-hour consultation with nursing staff, as needed
- State-of-the-art pain and symptom management
- Emotional support and counseling
- Spiritual support
- Bereavement support
- Medications needed for pain and symptom management
- Equipment needed for comfort
- Assistance with physical care
- Therapies as needed
- Volunteers as support



Chapter 1 I Will Help You Understand the Journey

Some questions you may be asking...



Who started the hospice movement and where did it begin?

The very first hospice, St. Christopher's in London, England, was started in 1967 by Dame Cicely Saunders. She was the first to recognize that terminally ill patients weren't getting the specialized care they needed. All too often, the medical community emphasized cure at all costs and viewed death as defeat and failure. Because of this attitude of denial of death as part of the cycle of life, terminal patients were frequently isolated. A "conspiracy of silence" was practiced where the diagnosis, prognosis, and any discussion of these tended to be withheld.

The worst fallout from this tendency to "treat the doctor instead of the patient" (pay more attention to the physician's comfort level than the patient's) usually occurred in the area of pain management. Pain tended to be treated with limited amounts of medication only when the pain became severe. Physicians feared psychological dependence and physical addiction to the drugs used to control pain. A cancer diagnosis was a dreaded death sentence because it almost certainly meant uncontrolled pain and stigma.

St. Christopher's hospice began the daunting task of changing society's attitudes toward the dying process, and in 1974 the first hospice was established in the United States in New Haven, Connecticut by Florence Wald, R.N., a former dean at Yale University School of Nursing. The first medical director was Dr. Sylvia Lack. In the decades since that first hospice opened its doors, thousands of others have sprung up in every corner of the nation.

*In recent years, the hospice concept has spread internationally with the needs of patients in every part of the globe for improved end of life care gaining international attention. Access to trained hospice and palliative care professionals in many of the world's nations is a serious problem. Studies show that over 100 million people in the world, dying of a terminal illness and often in severe pain, are not getting palliative care. **Help the Hospices** in the UK and the **International Association for Hospice and Palliative Care** based in Houston, Texas are organizations dedicated to improving the accessibility of hospice care, including adequate pain management, in all parts of the world.*

