MAINTAINING
COMPASSIONATE CARE:
A Companion for Families Experiencing the Uncertainty of a Serious and Prolonged Illness
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A MESSAGE TO THE READER:

This book’s content comes from health professionals, ethics specialists and family members who shared their stories in a conference titled *Maintaining Compassionate Care, Strategies to Prepare Family and Professional Caregiver Teams for Ethical Dilemmas of Caregiving*. The conference and the book focus on adults who have a serious illness or injury over a long time, but what the final result of their illness or injury will be isn’t clear. The stories in this book highlight common questions and frustrations discussed at the conference. The stories do not include all the situations that families and their loved ones face, but we want to share them because we believe you may find points like those in your own situation.

Your family member who has a serious health-related condition is referred to as a “patient” in this book. We know that to you this person is not a patient, rather a parent, a son, daughter, spouse or other relative or a close friend. We settled on the term “patient” because the situations described in this book all involve the caregiver team and the institutions of healthcare.

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*Project Co-Directors*

*The information shared in this book reflects the knowledge and experience of the authors as health care professionals and reflects the general discussion amongst conference participants, both health care professionals and family members.*
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This book is for you if you are taking care of an adult family member who has had a serious illness or injury for a long time.

This book is for you if no one can tell whether your adult family member will recover enough to go to rehabilitation, or instead, stay sick for a long time and then get worse and die.

This book is for you if you are in a kind of ‘grey zone of uncertainty’ along with the physicians and health care team.

This book is for you if you are unsure whether or not your family member will make enough steady progress to really get better.

This book is for you if you often have to talk with health professionals caring for your family member, but feel you don’t have enough information or are too stressed to get much out of these conversations.

We want to support you and make you more comfortable in your attempts to communicate with health professionals in these times of uncertainty. Uncertainty means not knowing how things will turn out. Uncertainty is a burden.

There are doubts, and no one can say how your loved one will do. Uncertain situations place special challenges on a family. You may have had discussions with your loved one over the years about what he or she would want in these circumstances. But those discussions don’t seem very helpful right now. Our goal is to help you to think about your situation, as you face important medical decisions.

Most of us count on the ability to ‘plan ahead’ as a way to have some control over our future. We tell the restaurant exactly when we will arrive
so that our table will be ready. The mechanic says the car will be repaired by Friday, and we go in on Friday and pick it up. We watch the morning news and decide to take an umbrella today even though there is sunshine as we look out the window, because the weatherwoman predicts rain this afternoon. We find an article on the Internet saying the price of electricity is going up, so we switch to gas heat. Our daily lives are full of plans made on the basis of a prediction by an expert. When the predictions turn out to be wrong and the plans don’t work out, we get frustrated.

It’s hard to deal with the uncertain circumstance you find yourself in. Although medical people are constantly coming up with new cures and treatments, there is still a lot that they don’t know, and a lot that they cannot do. When physicians and health professionals cannot make a prediction, the family cannot make any plans. This is very upsetting, and adds to the drain on family finances, time, and spirit.

When physicians and health professionals can’t tell you what will happen next, sometimes you just don’t feel like talking to them any more. Sometimes families turn away from the medical team, or fight anything they say. We have found that you are better prepared for whatever might happen if you stay involved with the health professionals as your loved one’s condition changes. This book contains ideas for how you can stay involved.

Many other families have gone through such uncertainty. They want to help you by sharing some things they went through, and the kind of help they found available. It is our hope that by reading the stories of how others have dealt with this kind of uncertainty, you might get some fresh ideas for yourself.

Some common questions family caregivers struggle with are:

- What is right for my loved one?
- What is right for our family?
- What would he say to do if he could tell us right now?
- Will she be able to tolerate the quality of life, even if she does
survive the burdens of treatment we are being asked to consider? Or, will the treatment be ‘for nothing’, with burdens experienced, and no benefit realized?

- How will the rest of us manage without him, if he dies?

What are the most important questions facing you? If you feel like doing so, jot them down here to refer to them as you read on:

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LOOKING AT UNCERTAINTY FROM A PHYSICIAN’S PERSPECTIVE

The Story of Mike

We want to tell you about a situation faced by one family. It is told from the doctor’s point of view.

Mike and his second wife Carol were in their late sixties, and had just finished raising their combined families. Carol was working as a school cafeteria employee, and Mike worked for the Highway Department. Mike was overweight, liked to drink a few beers every day, and rarely exercised. He had high blood pressure and diabetes, and despite Carol’s regular urgings, he admitted, “I don’t take great care of myself.”

Mike always said to those around him, “If I get real sick, I don’t want to live on machines.” One Saturday morning he woke up late, and called for Carol. “I …I can’t feel anything… I can’t move my arms and legs. What is happening to me? I’m really scared.” Carol called “911” and an ambulance immediately brought him to the emergency room of the nearby rural hospital. A breathing tube was quickly put in. Tests showed that Mike had a stroke. At this point, Mike could not talk and seemed unable to understand what was being said to him.

During an initial period of uncertainty after Mike’s stroke, both Carol and the health professionals went back and forth between the two predictions of the future for Mike. He was on the breathing machine, should it be removed? As Carol struggled to decide, Mike got a little better, and didn’t need the breathing machine anymore. But he was paralyzed, couldn’t swallow food or respond to questions. The physician and speech language pathologist told her that a feeding tube could be put in. What should she do? The neurologist couldn’t be sure if Mike would be able
to move on his own again. As a result of this uncertainty, she and the health professionals became frustrated in their attempts to plan for Mike’s care. It was too difficult when the future was so uncertain.

**A PHYSICIAN REFLECTS:**

Patients and families often don’t realize that there is a lot of uncertainty in medicine. They can’t understand why every question about treatment doesn’t have a clear answer. Physicians make decisions using the best evidence available from research. They also use their knowledge and past experience with patients with similar conditions and diseases. However, every patient is unique, and research findings are not able to clearly guide every patient’s case. The truth is physicians often cannot accurately predict what will happen to a particular patient.

In Mike’s case he got sick very suddenly. His future was not at all clear. And his wife Carol had to make heart breaking decisions about his care without knowing what would happen to him. The health professionals told her, “Mike might in fact get worse soon enough, but it’s also likely that he could live like this for many, many years. It’s just impossible to tell right now.” Carol was stunned and could not absorb what was said. The health professionals were divided as to how this would turn out for Mike, so Carol was left with a confusing picture of the future. As a doctor I felt responsible for trying to keep the healthcare team working together with Carol.

We didn’t know what would happen to Mike. This was a time when we had to keep talking to each other, even though there was a lot of frustration for both Carol and the healthcare team. The healthcare team needed time to figure out how Carol would absorb the information to guide her decisions for Mike. The healthcare team wanted her to understand all of the information so she could consider what was best for Mike. They wanted her to think about what Mike would want and what he valued.

Once ‘that which is medically possible for the patient’ is better understood, the family, patient, and healthcare team may be able to set the goals of care that are appropriate for a patient at the present time. Family members are essential here. Pictures, stories or something he or she made, help the
team get a feel for this person.

Here are some general questions that only Carol could answer since Mike couldn’t speak for himself. We asked Carol to consider them so the other members of the healthcare team and I could get a fuller picture of Mike as a person.

- Who is this patient?
- What did he like to do?
- What might his goals be for life, both for now and for later on?
- What did he hope for?

We have said that the family and the healthcare team should keep talking in uncertain times. One idea to discuss is how much better the patient would have to get after a certain treatment for the family to feel okay about saying yes to that treatment. Often people think the only choice is whether or not to start the treatment. Another option is a “time-limited trial.”

A “time-limited trial” allows treatment to continue, but only for a time that everyone agrees on, to see if the patient responds favorably to the treatment. This allows the patient’s condition to become more clear. The trial should be consistent with the general goals of care and goals of recovery.

It is important to agree on the length of the trial in advance. If the patient does not seem to be making progress, the treatment in the time-limited trial can be stopped. Family members should feel free to suggest a time-limited trial.

As a physician I try every day to remember that patients, family members, and health professionals have their own values and beliefs. Each of us will
see the situation from our own point of view. Even if we have many good talks, we won’t always agree on everything.

Getting an outside point of view can help us when we don’t agree. I often suggest inviting in a consultant from an ethics committee or a palliative care service. They might be able to provide a new idea or point of view. This often leads to some agreement on what to do next. I encourage family members to ask about these resources if they feel stuck in trying to get their point of view across to the healthcare team.

Institutional Ethics Committee ••• Advisory Group
Made up of health care professionals, chaplains and community members in a health care facility that provides guidance about ethical questions to patients, families and health professionals in challenging situations.

If you feel like doing so, jot down your thoughts here:

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Palliative Care Service ••• Group of interdisciplinary professionals, including doctors, nurses, social workers and chaplains that help patients and their families who are faced with a terminal illness make decisions and obtain treatments that will provide the very best quality of life for the time left.
COMMUNICATION BETWEEN FAMILIES AND HEALTH PROFESSIONALS

“The people who come to us bring us their stories. They hope they will tell them well enough so that we understand the truth of their lives. They hope we know how to interpret their stories correctly. We have to remember that what we hear is their story.”

Robert Coles, MD
The Call of Stories: Teaching and the Moral Imagination, 1989

“I kept telling them this is not my son speaking when he says he wants to drink liquids, even though it could make his situation more life threatening. I know my son would want to live! Finally, the nurse heard me!”

Nancy Gillespie, Mother of patient

You as a family member will be asked to work closely with the health professionals caring for your loved one. You may sometimes find these discussions helpful, and sometimes you may not.

In the pages that follow, we offer ten suggestions to help with these discussions. To show how these suggestions might apply to one particular situation, we present the story of Vicki.

Vicki was in a motor vehicle accident when she was 20, resulting in a spinal cord injury that left her paralyzed from the neck down. She had a very rocky start, with a few years of frequent hospitalizations, infections, and surgeries. Her father, Henry, was always at her side, and was her primary spokesperson when decisions had to be made.

Vicki became used to her injury. She returned to college where she became a teaching assistant in the English Department. When Vicki
turned 26, her medical problems returned: chronic infections, breathing complications due to food and liquids getting into her lungs, and stomach problems which made it hard for her to absorb nutrition, and also made her lung problems worsen. She spent the next year going from the hospital to the rehabilitation facility, only to quickly return to the hospital with fevers and pneumonias.

At one point she had a very serious pneumonia from liquids getting into her lungs while she drank, so the doctor ordered, “No liquids by mouth.” After a week of this, Vicki wanted desperately to drink liquids against doctors’ orders. “I’m old enough to make up my own mind,” she shouted. “I know the risks, give me something to drink!” Everyone was at a standstill.

Vicki’s father Henry told them, “No, that wouldn’t be right. Vicki will beat this and get better.” He was not ready to allow his daughter to die and thought she was not speaking from a deep place of what she really wanted although she was, by law, an adult. He argued, “Vicki should not be given liquids now, no matter how strongly she demands them. I don’t want her to inhale anything into her lungs again, and create another infection there.” Some health professionals agreed with Henry, some with Vicki, so soon there were two camps.

In this case, it was not certain what was going to happen. But the people didn’t quickly choose one course of action. Instead they kept talking and tried to support each other, and this seemed to be helpful to them.

We offer the following additional suggestions for your discussions with health professionals:

1. Let the health professionals know how much say you want to have, or do not want to have, in decisions affecting your loved one’s treatment. For Vicki, she had always made it clear to the healthcare team that she trusted her father, and knew he had her best interests at heart.

2. Try to clarify and agree upon what is known and unknown. It may be difficult for you to hear a physician or other health professionals express uncertainty about the care of your family member. In fact, you may notice that some health professionals are uncomfortable themselves when they find that they cannot give you exact information about everything.
3. Identify one or two health professionals whom you feel hear your concerns especially well. Each person expresses caring and compassion in their own unique way. This is true of family members and health professionals. Vicki’s father Henry was able to do this, and thus a plan that was acceptable to all concerned was developed.

4. Accept the fact that it won’t always be the same doctors and nurses who care for your loved one. You will have to take the time to get to know each health professional’s working style. However, the story of your loved one does not need to be lost in this process. When medical teams or nurses change, information about your loved one is passed on to the next team through the medical record. You can also give other key information in person. Request any help you need regarding your ongoing discussions with the new medical team members.

5. If you do not feel comfortable with these requests, you can ask to have help with these decisions. Sometimes health professionals will be handing you some very difficult decisions. Here are some questions you might ask:

   - What would you do if this were your family member?
   - What are the benefits of this treatment? Do the benefits outweigh the burdens of the treatment?
   - How exactly will this treatment help my loved one?
   - Could this make the situation worse and if so, how?
   - What degree of pain and suffering will this cause?

Vicki’s story does not give us the details of Henry’s discussions with staff. But we can imagine him asking these questions before making a decision.

6. Tell the health professionals about the demands on your life and the schedule that you are able to keep at the institution where your loved one is a patient. The healthcare team also has schedules to meet and cannot always be available. All involved will need to be flexible in planning meetings and conversations.

7. Before going into any meeting or conversation, make a list of all your questions and concerns. At the meeting, share them openly with the
appropriate care provider. Be accepting of an honest, “I don’t know” answer. Don’t hesitate to provide any additional information you think would help.

8. Have someone you know and trust go with you to this meeting. You may not be able to remember all the points of this discussion and a second set of ears is most helpful. You might choose a neighbor, another family member, an old friend, or your religious leader.

9. Take notes of the discussion. Your memory in times of stress is not always dependable. Some people find a notebook more helpful than carrying around many sheets of paper. Write down names and phone numbers of contact care providers, and provide the same on behalf of you and your family. Ask for pictures, pamphlets, charts or other materials that can help you remember.

10. Identify your primary language to the healthcare team. If English is not your first language, ask that an interpreter be available even if you think you can understand most things.

What areas of communication might you need help with now? Make some notes here:

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One theme of this book is that the uncertainty of illness presents many challenges for families. A prognosis is the health professionals’ best estimate of what will happen. For physicians and health professionals, uncertainty of illness is often translated into ‘uncertain prognosis.’ In the midst of uncertain times in the patient’s illness, it is often difficult to make decisions about treatments.

Most medical treatments are aimed at what health professionals call “the goals of care.” In establishing goals of care, one must take into consideration the patient’s medical prognosis along with the patient’s values and preferences. A good way to describe medical prognosis is to say: What is medically possible for this patient? Can the best possible medicine and surgery help this patient recover to an acceptable quality of life?

Once a medical prognosis is established, or defined as ‘uncertain,’ the patient’s values and preferences must then be added to the equation. How to best learn the patient’s values and preferences are explored in this section. Goals of care can be worked on together by health professionals and families, and of course patients themselves whenever possible, through a sort of blending of, and guiding by, prognosis and patient values and preferences.

Treatment choices are aimed at one of three general goals of care, and are tailored to the individual patient and his/her situation. The first possible goal is to try to cure the disease. The second possible goal is not to cure, but to improve the patient’s condition enough to enjoy some of life’s pleasures despite the disease. The third choice is to prepare the patient for a comfortable and dignified death.
**CONSIDER YOUR LOVED ONE’S VALUES**

A value is a belief or standard that guides the actions of an individual or group. Values are often so much a part of our daily lives that we may not be fully aware of, or ready to speak of our own values, let alone our loved one’s values, if and when asked. Our values are both cultural and personal. They develop early in life and are shaped by life experiences. Because our values influence our behavior, it is a good idea to take the time to examine our values when making health care decisions.

Think about something your family member believes is very important. You have probably identified a basic value. Ask yourself the following questions:

- When all is said and done, what is the most important thing in my loved one’s life?
- Why is that so important to the person?
- Is this in conflict with what others in his/ her life think is most important?

Now, try to think about a difficult or important decision that the patient made.

- What do you think most influenced his/ her thoughts or feelings for the decision?
Were there any regrets expressed after making the decision? Did he/she feel satisfied later on that it was the best decision?

All of these questions can help you identify your loved one’s values.

Different people have different values. Sometimes people in the same family have different values. This is one reason people act differently in the same situation.

What you value most as a patient’s relative may be different from what the patient values. When you are making decisions for a family member, you should decide as he or she would. This is difficult to do, but ensures that the decision best reflects the patient’s values.

A good exercise is to think over the following questions:

- What would my family member say in this situation?
- How would he/she express it in words?
- What aspects of ‘quality of life’ would be important for my loved one to have a ‘good day’?
- Does this illness take away those good days?
- Is there any hope of returning to ‘good days’? Or is my loved one going through many difficult treatments, and still not likely to return to having what he or she would call a ‘good day’?
- What is the patient’s quality of life in this day-to-day existence?
- Can the healthcare team imagine a time when your loved one might be able to leave the acute care hospital? Do they think your loved one would make progress in a rehabilitation hospital?
- Is it possible for your loved one to go home? Or would he or she have to spend the rest of life in a nursing home or chronic care hospital?

Think about the best answers to these questions. Find out what the health professionals think about the progress the patient might make. All the members of the healthcare team can help clarify the chances that the
patient’s medical condition will improve or get worse. Gathering this information will sometimes help you move towards a decision.

When the patient cannot presently speak for him/herself, but has left an advance directive, either verbally or in writing:

When the patient cannot presently speak for him or herself, someone will have to speak for the patient. The patient may have written down some preferences, or discussed them with family members, or even made casual statements that someone can recall. Some patients may have named the person they want to make decisions for them if they can’t make decisions for themselves.

These are all forms of “Advance Directives.” Advance directives can help a family member present the patient’s values and preferences to others. Patients who have completed advance directives can help family members and health professionals put together a plan that reflects the patient’s wishes.

For those patients who have provided some form of advance directive, we offer the following suggestions for family members faced with decisions:

- Review the patient’s written advance directive. Talk at length with the patient’s “health care proxy.”

- Discuss the values and preferences of the patient with those who know the patient using the advance directive as a guide. Include persons who know the patient from a variety of roles, such as family, friend, clergy, and if appropriate, co-workers.
• Talk with the healthcare team so that together you can understand your loved one’s advance directive.

Does what you learn about the patient’s values and preferences help in the patient’s current situation? How do each of the treatment choices fit with your loved one’s values, wishes and preferences?

**Health Care Proxy • • • A type of advance directive, recognized in Massachusetts, in which a person appoints someone age 18 years or older to make health care decisions for him if he is unable to make such decisions for himself.**

When the patient cannot speak for him/herself and has not left an advance directive, the following suggestions might help:

• Talk with family and friends about how your loved one lived his life, and what he/she revealed about his/her values by the way he/she lived.

• Consult with your loved one’s primary care physician, who may know the patient’s wishes.

• Reflect on your family member’s suffering. How do you feel about your loved one’s response to the treatments that maintain his/her life?

• What might a concerned community of others decide for this patient in similar circumstances?

When the patient can communicate in some meaningful way:

Any patient who can communicate should be part of the discussions about decisions to be made. However, be aware that not all cultures follow this practice.

• Invite your loved one to talk about what this is like for him or her.

• Expect changes in your loved one’s feelings about the decisions to be made. At any point in the long journey of serious illness,
your loved one may want to discuss what treatments he/she may or may not want. You may find that, at some point, your loved one wants to talk about how he/she feels about the situation, and the impact it has on his/her life.

- Your loved one may also like to tell you about symptoms such as pain, difficulty breathing, difficulty moving, or having to stay in bed with tubes and monitors keeping them alive.

- Continue frank discussions with health professionals in the presence of your loved one and members of the family. It may be time to start discussing the difficult topic of whether to limit life-sustaining treatments, or to forge ahead in hopes of some recovery.

- Your loved one may be thinking, “Enough is enough” or “Let’s talk about where we are going to draw the line.”

- Some seriously ill individuals may find it difficult to raise these issues with family members because they do not want to cause their family more sadness and worry. The patient may need to know whether you will be able to go on without him/her if necessary.

- By allowing the patient to say what is on his/her mind, you can lift a burden from someone who may have endured a long illness with many painful treatments.

At times discussions can be difficult, but such discussions and the passage of time often lead to the patient’s prognosis becoming clearer. Also, when you share a lot of information about the patient’s values and wishes, everyone involved can be better informed. By doing so, you may feel better prepared to make difficult decisions.

This is especially true when the burdens of these treatments outweigh the benefits, and the treatments are not helping the patient meet his/her goals for recovery. It is important for you to know that from an ethical and legal standpoint, it is permissible to refuse life-sustaining treatments, or withdraw such treatments after they have been started.
Jot down some notes about your loved one’s values and preferences, as you reflect upon the ideas presented in this chapter:

Notes:
FACING SOME CRITICAL JUNCTURES IN YOUR LOVED ONE’S PROLONGED ILLNESS

“Illness refers to how the sick person and the members of their family or wider social network perceive, live, and respond to symptoms and disability.”

Arthur Kleinman
The Illness Narratives: Suffering, Healing and the Human Condition, 1988

A serious illness can be viewed as a journey. The travelers include the person who is ill, his or her family, and those they love. You all may feel like you are making this journey without a map or any directions. The journey can leave everyone feeling uncertain and confused.

Family members are often asked to make many decisions about various medical treatments, some of which might be life-sustaining treatments. The decisions you are asked to make may change the situation of the person who is so very ill. We call these “critical junctures” because they occur at a critical point in the journey you are on, and the decision made may well affect the patient’s outcome. As you were reminded in the previous chapter, it is best if the patient had the opportunity to discuss and plan for these events in advance. This preparation may then allow you and the health care team to make decisions that will be most in line with the patient’s values.
At every critical juncture, you will want to ask about the benefits and burdens of each treatment decision. You will want to ask how the decision may affect your loved one’s quality of life.

The following six examples illustrate some common decisions about treatments that you may be asked to make at critical junctures. When considering these treatments with the healthcare team, be sure to think carefully about the goals of care for your loved one, as previously discussed.

1. Breathing Tubes

“If my loved one develops difficulty breathing, do we want to put in a breathing tube and use a mechanical breathing machine?”

A breathing tube is connected to a mechanical breathing machine, commonly called a ventilator. A breathing tube can help patients who have a sudden serious change for the worse in their condition. When making a decision related to breathing tubes and ventilators, you may want to ask the health team:

- When the acute event has improved, can the breathing tube and ventilator be removed?
- What happens if my loved one’s condition does not improve, and he/she is dependent on the ventilator to live?

The initial breathing tube may be placed through the mouth into the throat. This tube can irritate the mouth and throat. So it can only remain in place for a few weeks.

Another type of breathing tube can replace the initial breathing tube. It will be placed through a surgically made opening in the neck into the trachea. This tube leads to the lungs. You may hear this referred to as a “trach” (pronounced trake), which is short for tracheostomy tube. The tracheostomy tube is a more permanent breathing tube, and can remain in place for as long as needed, with or without a ventilator.
2. Cardiopulmonary Resuscitation (CPR)

“What if my loved one’s heart stops beating?”

Another decision you may be asked to make is what to do if your loved one’s heart stops beating or he/she stops breathing, commonly called cardiac arrest, or cardiopulmonary arrest. The treatment in question is cardio-pulmonary resuscitation, more commonly known as CPR. This life sustaining treatment is ordered with the hope of making the heart-beat return to a normal rate and rhythm. It involves health professionals pressing down hard on the chest in order to try to pump blood through the body, and delivering shocks to the heart. In addition the patient will receive artificial breaths through a mask into his/her lungs, and be injected with a number of medications to stimulate the heart beat and blood pressure.

The physician and health professionals caring for your loved one may recommend that CPR not be given. When physicians and health professionals recommend against CPR, they are doing so with knowledge of patient conditions where CPR is known not to be effective. The doctor’s order not to attempt CPR is called a DNR (Do Not Resuscitate). Once the DNR order is given, all members of the health team are told that resuscitation will not be attempted. However your
loved one will still be cared for and will receive any other medical treatments that support the goals of care for him or her.

**Do Not Resuscitate (DNR)** ••• An order to not attempt cardiopulmonary resuscitation.

### 3. Feeding Tubes

*“If eating is no longer possible do we consider a feeding tube?”*

A feeding tube may be considered for several reasons. Your loved one may lose some or all of the ability to eat and swallow. This problem may place your loved one at increased risk of passing food or fluids into the lungs. This leads to what is referred to as “aspiration pneumonia.”

Initially the feeding tube is placed through the nose and throat and then into the stomach. This type of tube is usually used for just a few weeks. After this time, or initially for some patients, a feeding tube may be placed directly into the stomach. This procedure may be done by a surgeon or in the radiology department. You may hear this referred to as a “gastrostomy tube” or G-tube. If a feeding tube is placed, your loved one will be fed a liquid formula, either on a scheduled basis or continuously.

Some persons who are very ill decide not to choose a feeding tube as a treatment. In this situation the ill person and their family should expect the support and direction of health professionals in providing comfort and reassurance to both patient and family. Research suggests that seriously ill persons who are on a trajectory toward death who do not eat or drink do not suffer from hunger or thirst.

### 4. Intensive Care Unit (ICU)

*How can we decide whether or not to move my loved one to, or back to, the Intensive Care Unit?*

Patients will endure many types of treatments over the course of a long illness. Sometimes it seems that the patient is making gains. On
other days, it may seem that there are only setbacks. When there is uncertainty, the patient may choose to endure it.

At some point in the illness, the physicians and other health professionals may suggest that adding more treatments might be too burdensome. They are not proposing to withdraw a particular treatment, only not to give additional treatments. One example of this is whether to go to, or return a patient to, the intensive care unit.

Sometimes going to the ICU is a compromise, or a time-limited trial, to see whether the patient will recover somewhat or else start an approach toward death. Family and health professionals may decide to continue to care for the patient on a general unit, even if a medical crisis occurs. This decision may mean shifting the patient’s goals of care from cure to comfort.

5. Transitions – going home or to another facility

“When and how do families and health professionals come to the decision to transfer the patient from the acute care institution?”

You may have already had to make decisions about continuing or discontinuing medical treatments. You may also have to think about, with the health professionals, where care of your loved one will be provided.

Families of patients with prolonged illness are sometimes faced with decisions about moving their loved one to a skilled nursing facility, rehabilitation center, nursing home or inpatient hospice. Another decision may be to take the patient directly home. The patient’s nursing needs will help to provide direction about where the best care setting for the patient might be.
It is important to remember that home care is a 24-hour, 7-day a week job. Caring for a very ill loved one in the home can be demanding and scary. Community health agencies, home hospice, and friends may be of assistance. Some families have the resources to pay for extra care providers in the home. Caring for an ill loved one at home can be both challenging and rewarding for the family. Factors to consider when deciding to take your loved one home include the burden of care required to insure the patient’s comfort, the duration of life as it can best be predicted by the physician and nurses, and the degree of supports in the home. It is not for everybody to care for a very ill person at home, and if it doesn’t seem possible for you and your family, please do not feel guilty in saying so.

6. Concerns at the end of life:

“What if my loved one’s condition does not improve, and it becomes clear that he or she is going to die?”

If recovery is not possible, you may find it difficult to discuss with your loved one where and how he or she wants to spend the last weeks or days of life. The chances of going home may depend upon the condition of the patient. For some patients, going home may not be possible, but ‘part of home’ such as favorite music, blankets, pictures, etc. may be brought into the hospital.

Your loved one may not be able to discuss these concerns. You and the family may have to decide how your loved one would want to live until the end of his or her life.

The decision is easier if you look at the person’s whole life as it was lived. Try to find the space, time, and personal resources to help your loved one reflect with you about this if he or she is able. Patients often have feelings about this. These talks may provide you with some satisfaction and comfort at a time of profound sadness.
If you feel inclined to do so, make some notes here about critical junctures you may find yourself facing in the near future:

Notes:

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STRESSES, COPING AND FEELINGS

The following story is told by a patient’s sister. It could just as well have been told by a nurse, physician, chaplain, speech therapist, or other family member. We present it in three parts, and use it to illustrate a few of the things we discuss in this chapter.

I love these words from the Book of Ruth, “Do not press me to leave you. . . Where you go, I will go.” My eyes scan the room. My dear sister Ruth lies in her hospital bed surrounded by her immediate family, breathing with the help of a machine. One tube feeds her body, another drains her body’s waste. A dialysis machine cleans her blood since her kidneys no longer function. Her lungs are bad; her heart is failing, dependent on medication.

“With so much of her body failing, what keeps her here?” I wonder. Surely she must be suffering. She has been in this small room for months. She is completely alert and visits with her husband and children several hours each day. She wants to stay. Her family wants her to stay. She is not pressed to leave.

Stress

A long illness with an uncertain future may present a variety of new stressors for you as a family member of the patient. There could be extra demands on your time and energy. There might be more worrying, financial concerns, challenges to your faith, loss of control, changed routines at home, less leisure time, being less efficient at work. But the most stressful image of all is to see a loved one suffer. It affects family deeply, and health professionals as well.

Sometimes people do not realize how stressed they are or why. They may feel generally anxious or “just not right.” We have made a list of some
common stressors below. This list may help you to understand just how much stress you are experiencing. By understanding your stress, you may be able to cope and feel better.

- **Physically**, the extra demands on your time and energy can be quite stressful. Sometimes lack of sleep or changed sleep patterns can lead to chronic overtiredness or exhaustion. Changes in appetite can result in not eating enough or eating too much. This can lessen your ability to fight colds and illness. Headaches, upset stomach, and other body aches increase your levels of stress.

- **Psychologically**, you will worry about the sick person and feel a roller coaster of strong emotions. This will raise your level of stress.

- **Spiritually**, you may feel that you are losing your faith. You might feel anger at God. You might feel abandoned by God. You may sense that life is losing its meaning. All these things can increase the stress you feel.

- **Strained relationships**: Caring for a sick person for a long time can affect your marriage. The children may act up when they have less time with you. You may find yourself fighting with other family members who see the patient’s illness differently. They may disagree with you about difficult decisions. All these things can intensify your stress when a family member is seriously ill.

- **Socially**, you may have less time to visit with friends. On the other hand, you may find that friends are demanding even more of your time in their desire to be helpful. These stressors can bring on feelings of isolation and anxiety. Your stress level will remain high if you do not have as much time to relax.

- **Money problems** may raise your stress level. You may fear losing wages or health care coverage. There can be additional expenses when you travel to the institution where your loved one is being cared for. There are parking fees and more meals out, and perhaps more child care costs. You also may worry about the future. Perhaps you will have to provide more care and equipment at home. Perhaps you may have to find money for the nursing home or
homecare in the future. All these added worries are a normal part of responding to the stressors of a long sickness.

- **Work** stress can also increase. You might miss work time or lose concentration when at work. You may fear that your poorer job performance may lead to losing your job or missing an opportunity for a raise or promotion. It certainly can make you feel less confident about yourself.

Ruth’s time with her husband and children is constantly interrupted by treatments from nurses, the physical therapist, the doctor, and the many other caregivers on her team. She hasn’t eaten on her own in months. She has lost her privacy and most of her control. She is dependent on people and machines to keep her alive. Her lips are dry; her skin is gray, her eyes are tired. I look at her and remember Ruth in her youth, such a wonderful sister, caring for our siblings and myself when our parents weren’t able to do so. She has given so much, why does she have to suffer so now?

But she hopes, as she always has. She wants to go home again, to live with her husband and family. With all her remaining strength and determination, she endures all, hoping to conquer this illness and be with her family again. She can’t imagine leaving her husband alone. She is convinced he and the children couldn’t survive without her and they believe her. “Where you go, I will go.”

I get chills entering my sister’s room. What I believe and hold dear is challenged in this space. I recall all that Ruth has given to others over the course of her life. Spending time at her bedside means facing suffering previously unimagined. Of course, we hate suffering. We try to avoid it, attempt to alleviate it, do anything to live through it. Yet once we are in the midst of it, what can we do?

**Coping Styles**

Dealing with serious illness means coping with uncertainty. Each decision becomes life-or-death: a turn toward a way of living with suffering or toward ending suffering. The room Ruth lives in is a place beyond rules. It’s a place where we all bring what we value most: what we hold
Dear and are afraid to lose. To face this alone is very difficult. Joining forces is our best hope. We need each other to help with all the decisions.

Each additional stress we feel adds to anxiety and tension. That anxiety and tension build. At some point, we begin to feel overwhelmed by it. This is when we have to use some other ways to lower anxiety. We have to “cope.”

Coping helps us lower our anxiety so we can continue to meet the demands of the day. It is how we keep from being overwhelmed by all of life events. For example, if the big picture is too much for us to think about all the time, we focus on just today. Perhaps we would choose to keep track of medicines, or make sure the nurse visits the room every half hour. We may feel a regained sense of control by learning about the disease. We may back away from the person so we won’t be so hurt when they get sicker. These ways of coping are needed just to get by each day, and we use them all the time.

Each person has a different way of coping. Most people rely more heavily on one or two things. People familiar with us can recognize certain patterns of behavior as our main coping style. No style is right or wrong, however some coping styles may be more or less effective in particular life situations.

We have said that the level of stress is different for each individual in the family. It is the same with coping styles. Coping styles depend on what you are like as a person and your role in the family. They often depend on your personal and family history of coping with illness and crisis in the past.
Below are a few examples of coping styles.

- **The person who pulls back and tries to get some distance.** Persons using this style do not look for much information. They often want to deal just with bare facts rather than their feelings. They may visit the patient less frequently in order to keep their anxiety down to a level they can handle.

- **The person who wants to get closer to the patient and more involved.** They come in for long or intense visits. They seek information and want details that may be irrelevant to their roles as family members. They may appear watchful of health professionals’ every move. They may be critical of care and may become angry easily. They may get deeply involved in details of the loved one’s condition. A person using this style is not usually able to engage in the big picture. They can keep others from talking about how serious the illness is. They avoid the feelings that accompany thoughts about the future.

- **The person who tries to maintain control by planning.** People using this coping style may continuously look for a timeline and want to know what will happen and when. They seek predictability and order in the midst of uncertainty and chaos.

- **The person who becomes overly optimistic.** They must always see the glass as half full. They often voice hope for miracles. They may try to convince everyone that the next treatment will work, despite the reservations of the health care team, and other family members. All of these protective stances reveal how anxious the person is.

In describing some coping styles we wanted to assist you in understanding some of your own reactions and those of other family members. This may make working together easier.

In the story we are presenting in this chapter, Ruth’s sister is coping by focusing on the present moment and on her love for Ruth. She is searching for some meaning in the suffering she sees.

Ruth herself seems to benefit from doing anything to be with her family.
She feels strongly that they need her. She tolerates the suffering so she can relate to her husband on an intimate level. This is how Ruth keeps her anxiety at reasonable levels. She does not succumb to despair.

Her sister remembers their childhood together. She recalls that even as a teenager, Ruth responded so maturely to the needs of her younger siblings. This helps her find meaning in Ruth’s life.

She wonders why Ruth and her immediate family have decided to keep going despite Ruth’s suffering:

*Why doesn’t Ruth let go? Why doesn’t her husband let go? What are they holding on to?*

“Stop,” I say to myself as I feel my anger rising. My anger is real and is present in this room, as intense as the connection between Ruth and her husband. Our energies are not opposed but are part of the love and care we give to Ruth. We wrestle to come to understanding.

“What keeps her going?” I wonder. How can Ruth keep up the fight in the face of such agony? Can’t she or her husband or the medical team see the anguish in pressing on? Why not stop the procedures, the tubes and drains – there is so little hope of recovery. Then I see her husband gripping her hand, looking into her eyes as they silently ask each other the same questions in their own quiet way. The answers aren’t there, but their connection is palpable.

Another family meeting at Ruth’s bedside. The entire team of physicians, nurses and therapists paints an uncertain picture: given their very best efforts, the latest technologies and treatments, there’s only the slimmest chance Ruth will get better. Pressing on means more pain and there are no guarantees of success.

No one knows what to say. Ruth waves us gently away. She is not ready to decide. I am the last to leave.

The next morning, I arrive early, as I could not sleep. I am present for the healthcare team rounds. Ruth is trying to say something to the team. The breathing machine doesn’t allow her to speak, so someone must read her lips. I step forward and lean in to see my dear sister’s lips. I know her
thirst for life, I can read her dry lips and hold her with my eyes as she says, “I’m never going home, am I?”

I tell her the truth, “I don’t know.”

She pauses and mouths “I don’t know if I want this anymore.” What follows is a moment of silence that feels like an embrace.

Ruth’s husband is summoned. A new uncertainty - we huddle together. Ruth has brought us closer – there’s a feeling that staying connected will keep Ruth with us in spirit no matter what the final decision. We hold on to each other so we can let go.

**Emotions**

We have looked at stressors and coping strategies, now we will turn to emotions. It is true that there are many strong emotions involved with being a caregiver. These emotions are reactions to what is going on around us, as well as to what is in our thoughts. Several emotions that are often part of the long illness journey are guilt, anger, fear and hope. We saw some of these emotions in Ruth, her husband and her sister. We also would like to add some observations about courage.

**Guilt** is often part of the emotional territory for the family caregiver. Guilt gets triggered when family members ask themselves, “Could I have prevented this illness or accident from happening to my loved one?” “Why didn’t I check on my mother that day?” There can be many thoughts that begin with “If only I had done [such-and-such].” To ask these questions or have these thoughts again and again is normal. But they can spiral out of control and dominate our mood.

At the same time, it is not always easy to dismiss this line of thinking. Often looking for the reason why the illness happened is a search for some control in an uncontrollable situation. Even though blaming ourselves and feeling guilty are not comfortable, they can satisfy a need for control.

**Anger and frustration** occur often when we cannot control a situation. Family members, such as Ruth’s sister, may feel angry that there is little
they can do to help their loved one through an illness. Anger may be di-
rected at the patient or family, or at health professionals. However the real
target is often the illness itself. We get angry that the patient may suffer
more and even die.

Fear is another common emotion when a patient is sick for a long
time. Fear is made more intense by uncertainty. Family members fear
the death or permanent disability of their loved one. They, like Ruth’s
husband, may find themselves wondering how they will survive without
their loved one.

They can’t imagine how they will manage the care of that person if s/
he does survive. They don’t wish to think about how life will change for
them.

These fears may be realistic. It is not a matter of getting rid of your fears
but learning how to cope in spite of them. Fear, like guilt, may be lessened
if you are not sitting alone with it. Find someone who you can talk to and
who can really listen and not just try to talk you out of your fears. The
social worker and chaplain are good resources.

Hope gets tested in a long illness. At times, you may feel as though you are
on an “emotional roller coaster.” One day your loved one may show some
improvement, and you in turn feel some relief. Your hope gets recharged.
But the next day comes with changes for the worse, and you feel drained
of hope.

You may find you need to adjust what you hope for over time. You must find
different things to be hopeful for as your loved one’s condition changes.

For instance, you may always maintain the hope that your loved one will
live. But at the same time you may hope that if s/he cannot survive, the
death will be peaceful and without suffering. There is always something
to be hopeful for even in these very difficult and uncertain illness situa-
tions. Share your hopes with health professionals as well as your fears and
concerns. Both are equally important.

Courage is the ability to act despite your fears and feelings. Your courage
is shown in your behavior. You may not feel courageous by just being pres-
ent for your loved one, but it is a courageous act. It takes courage to ‘forge ahead.’ During the illness, you are doing things you never thought you could do. You are providing care, learning medical language, and talking to doctors and other health professionals daily. These are all acts of courage. Give yourself credit.

In summary, we urge you to be gentle with yourself. Decide to forgive yourself for mistakes along the way. Believe in yourself as one who is doing the best that you can.

The following are additional suggestions for caregivers:

- Take breaks while visiting. Take a walk, go for coffee or a meal.
- Use the hospital chapel as quiet time.
- Take a day off every now and then.
- Try to eat well and get enough sleep.
- Delegate tasks to less involved family or friends who want to help. Try not to feel you are burdening people. They have offered because they want a way to help.
- Ask for support in whatever way is comfortable for you – use the social worker, chaplain, your own clergy, friends, a diary or log book.
- Find a safe place to let yourself cry, rage, tremble, laugh, hurt, love.
- Identify some activity that helps you to relax and do it!
- Do not use your time at home to make long phone calls updating others. Call one person and designate him/her to spread the word, or use a web-based update.
- Spend time with your children, grandchildren, or other children you know. They are a healthy break from the intensity of the hospital or nursing home.
- Make your own list of what is helpful.
If you would like to reflect on your own situation from the material in this section of the book, you may like to jot down some notes here:

Notes:
CLOSING

This handbook has brought you through a journey. You have reflected on your experience as a family member or friend living through a loved one’s serious and uncertain illness. Your loved one’s illness has tested your strength in so many different areas of your life.

We hope that we have given you a chance to gain fresh insight as you go forward. We encourage you to share this with your family as a reference. We also encourage you to talk with the physicians, nurses, social workers, therapists and chaplains who are taking care of your loved one. They have a great deal to offer you at this challenging time.