

*Difficult* CONVERSATIONS  
WORKBOOK  
FINDING A PATH THROUGH ILLNESS

**Speak Sooner**  
ask questions now, live the answers  
a CENTER FOR COMMUNICATION IN MEDICINE initiative

## The inspiration for this workbook...

In 1999 I found my life and work taking a sudden turn when I was invited to serve as a patient advocate at a regional cancer center in Vermont. Before that point I'd thought of myself as a writer and artist—but it had never occurred to me that the skills I had cultivated as a writer might be useful in the context of healthcare.

In my new role I discovered they were. Illness calls for stories but telling doesn't come easy—nor does listening.

Time and again I would listen to patients talk about their experiences, and then read the words used in the medical record to describe their disease. **It was as if doctors and patients were speaking completely different languages.** Hearing the patient's perspective there was often fear, anxiety and the search for understanding of their diagnosis and its meaning—much of which they did not feel comfortable expressing to their doctors. Yet what was recorded in the patient's chart reflected the clinical language of medicine: vital signs, diagnostic terminology, and lists of symptoms, medications and treatment recommendations.

This disconnect was driven home one day when I had the following conversation with a patient:

**“I want to be a good patient,”** she told me.

As a writer I heard an opening line. At the same time, I understood that her definition of “a good patient” could be valuable information for her doctor to know. I asked her what she meant.

“A good patient,” she explained, “is someone who handles their disease well—who understands what their doctors tell them. I try not to let my doctors know if I don't understand something.” As long as she didn't say anything, they assumed she understood because, as she explained, “Doctors take silence for comprehension.”

She went on: “A good patient reads all the cues their doctors give and how they want you to be. When I am not doing well, and sometimes I'm not, I get frightened, sad, even depressed, but I do my best to mask it. Is there anyone who doesn't? **Do other patients mask it better than I do?**” she asked.

She said she didn't want to disappoint anyone, adding that she feared she would, because the cancer she had was not one that would ever be "cured."

Then she told me that it was more important to have a good doctor. "Good doctors know their medicine—they know its limits," she said. "Good doctors know they can't make [my cancer] go away, they can only hope with me it will continue to move slowly, very slowly."

I wrote down what she said—in her own words—and filed the note in her medical record. Reading it, her oncologist was prompted to ask in the next visit:

**"Tell me what you don't understand, and what you hope for."**

Candid conversations like this offer patients a clearer understanding of their medical condition and help doctors to be better informed advisors. Open communication increases the level of trust between patients and their healthcare team. As a result, patients feel like they have a role in their own care—whatever role feels most right to them.

But **these conversations don't happen all by themselves**. And for patients who tend not to be open and assertive about expressing their needs, or who do not have someone in the room urging them to speak up, expectations about the outcome of their treatment may not be thoroughly understood.

This workbook was inspired by patients, and created in collaboration with patients. It is our hope that through using it, more patients will feel empowered to begin these meaningful conversations sooner.



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## INTRODUCTION

No one is prepared for a diagnosis of a life threatening illness. Yet, facing such a challenge can both help us discover our own inner strengths and increase awareness of the resources that can offer needed support and encouragement. In the video, “Voices From The Lived World of Illness: Difficult Conversations,” five advanced cancer patients generously share their stories of living with incurable illness. Their firsthand accounts have been used to create this workbook but we recognize these experiences speak to similar concerns of those living with other types of chronic and incurable illnesses.

“Incurable” does not mean “untreatable”—but it does place both doctor and patient in uncertain territory. Cathy Ferree, one of the patients in the film, tells us that her doctor assures her, *“There are lots of things we can try.”* Laura Byrne, another patient, observes, *“Doctors have a hard job; they need to feel their patients out... not everybody wants to have these conversations.”*

In our years working with medical professionals, patients and families, we have heard again and again that doctors and patients can be equally reluctant to speak openly about incurable illness—something echoed by the patients in this film. Yet avoiding these difficult conversations can result in a lack of information about and preparation for critical choices, which can ultimately cause unnecessary suffering and regrets.

What patients understand—or misunderstand—about the course of their illness can affect the treatment decisions they make. Steve Williams, another patient, cautions the viewer, *“If patients don’t ask questions then doctors will think you understand everything they’ve told you. They don’t know what you know and what you don’t know.”* A working relationship between doctor and patient requires that the doctor understand that particular patient’s needs, goals and expectations of care—and the responsibility for arriving at that understanding must be shared between them.

This workbook has been designed as a tool to help patients identify their own issues and concerns and prepare for the challenging but vital task of communicating clearly and openly with their healthcare team and, of course, with their family and friends.

## **WHY WRITE?**

This workbook is not intended to “teach writing.” It prescribes the pen as a tool to help patients put words to their experiences. Studies show writing helps patients organize thoughts, identify problems and express how illness has changed their lives. This can help you better understand your concerns, explore choices, and find the confidence to communicate your own wishes in the course of your care.

We believe that accessing thoughts and feelings in response to these questions and prompts can be key in helping patients navigate the challenges of illness with their deeply held values as compass. It is not simply mind over matter but what’s on your mind that matters. Writing works!

## **HOW DOES IT WORK?**

The Difficult Conversations Workbook can be used on its own or in conjunction with the video. The numbering of chapters in the workbook corresponds to the sequence of chapters in the video. Whether or not you are using the video, we suggest that you begin the workbook with Chapter 1 and continue in sequence. Each chapter builds on the next.

Illness forces us to ask ourselves: what’s happening to me? With that in mind, the exercises in this workbook open with questions to help you think about your own experiences in search of an answer. Opening prompts guide you into the writing itself. Write the first thought that comes to mind, and stop when you complete that thought. You are not being asked to complete the workbook in one sitting. You can begin one question at a time or one chapter at a time. Proceed at your own pace.

Ask questions now, live the answers. Your answer is the right answer. Don’t worry about spelling, grammar or punctuation. No patient’s experience of illness unfolds as a neat and organized story.

What you think and feel about a specific topic may differ from one day to the next, from week to week or month to month. The one constant for most patients facing chronic or life-threatening illness is change itself. You may want to think about writing as “notes to yourself” or “thoughts for the day.” We recommend that you date your entries, and revisit the chapters in your workbook from time to time. Ask yourself: do I have any new or different feelings and thoughts about this topic today?

## **WHAT DO I DO WITH THE WRITING?**

This workbook is intended for your own personal use. The purpose of completing the exercises is to help you better understand your own issues and concerns in preparation for your office visits. It is not required that you share your writing, but we do suggest that you bring this workbook to your appointments, so that you can refer to what you have written in order to help focus your conversations with your doctor and healthcare team.

## **WHAT IF I AM NOT COMFORTABLE WRITING?**

It is not a requirement that you write. However, we do recommend that you take the time to go through the workbook and reflect upon your own responses to each writing exercise, which will help prepare you for your appointments.

## **OUR HOPE**

In the film, Laura Byrne echoes our hope as well as the hopes of patients, families, doctors and healthcare professionals everywhere when she says, "*I hope there's a way to make it easier.*" If this workbook can help patients think through their own needs, goals and expectations and feel better prepared to participate in decisions about their care, then it will have achieved its purpose.

We believe the most difficult conversations can also be among our most meaningful ones. A workbook may not be able to make these conversations easier—but we hope it will help pave the way so that they can take place openly, honestly... and sooner rather than later.

Let's begin...

## Chapter 1 Understanding Your Prognosis

Until it becomes something you must think about firsthand, the word “prognosis” can seem unfamiliar, even abstract. Many patients feel uncertain about what their prognosis actually means, even after speaking to their doctors.

Laura doesn’t even remember having been given a prognosis... But, she admits, “I didn’t really want one.” Later, she says, she “poked around enough to find one,” but discovering she didn’t like what it said, she “kind of ignored it.” Rich was told that his condition was **“treatable but not curable.”**

*Prognosis, treatable and not curable are hard concepts for doctors to explain and can be even harder for patients to understand.*

Steve’s doctor told him, “It’s good and bad.” Fritz was told that if he didn’t proceed with more radical treatments he had six months, maybe a year, to live. “That was a bad day,” he said. Cathy recalls that her doctor said “it’s not curable but it’s treatable; we’ll make you comfortable, **there are lots of things we can try.**” Recalling this, she adds, “That was hard to hear.”

Ask yourself:

What do I remember my doctor saying about my prognosis?

I remember my doctor saying...

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Illness is a world with its own language and the terms themselves may not have the same meaning for both patient and doctor. Because your doctor may not realize this, it will often be your responsibility, as a patient, to ask for clarification on any issues you might not understand.

Ask yourself:

What do I understand “prognosis,” “treatable” and “not curable” to mean?

I understand “prognosis” to mean...

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I understand “treatable” to mean...

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I understand “not curable” to mean...

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## Chapter 2 Coping With Unwelcome News

No two people will react the same way to their prognosis. Some people want more information—others may prefer less. Oftentimes, feelings can change, or evolve over time.

“No question, you’re gonna be in shock, depressed, and so forth,” says Rich. “And then once the dust settles, you really have to say, ‘Okay, **now what do I want to do with my life?’**”

Steve recalls that upon receiving a prognosis, “You’re just overwhelmed.” Later, he says, “Even though things inside you might be ripping you up, or bothering you **you try to put on a good face.**” Cathy, says, “Denial can be a wonderful thing.”

Each of us finds our own way of coping with the shock of unwelcome news. There can be many ways to cope with your prognosis including spending more time with loved ones; trying to be “upbeat”, throwing yourself into work; beginning psychological counseling; pursuing spiritual insight; etc.

Ask yourself:  
How am I dealing with all this?

One of the ways I am coping with my prognosis is...

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“I tried to insert facts wherever I could instead of just raw emotions,” explains Fritz, saying that helped him to distance himself from the news that his illness was incurable. Laura tucks news about her health away in her mind so that she can go about her life, saying that habit becomes a problem when she discovers **“I can’t say and am not saying what I really feel.”**

Ask yourself:

Is my way of coping helpful in managing my emotional stress?

The way in which I cope helps me to...

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It has been said that silence is a form of speech. Some people don’t know what to say or what questions to ask. Do you find yourself not saying what you really feel?

Today I am feeling...

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Sometimes I find that I can’t really say what I am feeling to...

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## Chapter 3 Speaking With Family & Friends

Being ill can feel isolating. Of course it is true that your friends and family may not understand exactly what you are going through. But they may be having their own experience of illness--wishing to help but not knowing what kind of help you need. Bridging this gap isn't easy—but many patients find the support of others crucial as they cope with the challenges of illness.

**“I’m avoiding any possibly difficult conversations with my friends and family,”** says Cathy. “I put it off to another time—I just don’t want to deal with it right now.”

“I worry about how people can live with me,” says Rich, saying he knows his illness must be hard on his wife. Fritz, describing a critical appointment, says, “My wife was there—it was important to me that she understand exactly what I was facing.”

Ask yourself:

Am I avoiding difficult conversations with any of my family members or friends?

I’m avoiding conversations with...

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“I feel like I have to comfort and protect family and friends. **I resent that a little bit,**” says Cathy, admitting, “I’d like them to be comforting and protecting me.” Laura wonders if she is denying herself help from her family, saying, **“Maybe they want to help**—they don’t want to be protected.”

There can be many reasons to protect loved ones from being told about your prognosis.

Ask yourself: Whom am I protecting?

I find myself protecting...

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I protect them because...

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Many patients are so busy coping with the emotional and physical demands of illness that they forget there may be support available to them. **You may not be thinking about the kind of help you need, or you may not know how to ask for it.** Meanwhile, your loved ones may be equally unsure about how best to support you.

Ask yourself:

What kind of emotional support and practical help do I need from family and friends? (examples: compassionate listening; rides to appointments; childcare, prepare meals; etc.)

What I need from my family at this time is...

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What I need from my friends at this time is...

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## Chapter 4

### What You Need From Your Healthcare Team

Decisions about treatment can be harder to make as options become limited. Over time, your goals for care can change—and so can what you need from your doctors.

“We really want to know that [our doctors] care, that they’ll do the best for us... we need to hear that,” even if they can’t offer a cure, says Cathy. “[Doctors] don’t need to change the reality, but they don’t have to wipe out the hope,” says Laura, emphasizing that **“compassion is a big piece”** of the care she looks for from her doctor.

As a patient, communicating clearly about what you need most from doctors and nurses makes it possible for them to provide more effective and individualized care.

Even though Fritz values his physicians’ clinical knowledge, he says, **“My well-being, as a concept, and a goal, and a way of life, is more important than what they can do for me medically.”** Needing to be prepared for what he can expect, Steve suggests that doctors should, “write it all down.”

Ask yourself:

What do I need from my doctor at this time?

At this time, what I need most from my doctor is...

(examples: promptly returned phone calls or emails; candor regarding prospects for treatment success or side effects; written directions; respect for my preference for complimentary/integrative therapies or palliative care; etc.)

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**“Most meaningful is communication,”** says Rich, adding, “If I’m scared, or I don’t feel well, or I have a question, I can pick up the phone, and—relatively quickly—get an answer.”

Ask yourself:

What questions do I have for my doctor at this time?

I would like to ask my doctor...

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**Nurses work directly with your doctor and play an important role in your care.** You may, in fact, see your nurse more often than your doctor.

Ask yourself:

What do I need from my nurse?

What I need most from my nurse is...

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Ask yourself:

What questions do I have for my nurse at this time?

I would like to ask my nurse...

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Like many patients, you may be exploring the use of complementary therapies (also referred to as integrative therapies), such as herbs and supplements, acupuncture, massage, and mind-body approaches (like meditation) as part of your care.

If you are currently incorporating complementary/integrative therapies into your care, have you discussed this with trusted parties or with your healthcare team?

I have communicated about my use of complementary/integrative therapies with...

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Often, patients don't communicate with their healthcare providers about the use of complementary/integrative therapies.

I have hesitated to discuss complementary/integrative therapies with my healthcare team because...

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Is there anything you would like to share with your health care team regarding your use of or interest in complementary/integrative therapies? How would you like them to respond?

I would like my health care team to...

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## Chapter 5 Partnering In Your Own Care

Getting the care you need depends as much on your willingness to actively participate in decision-making as on your doctor's skill. Communication is the key to that partnership.

"I envisioned being part of this team, having calls with the doctors about possible treatments...where I would be able to participate, or at least listen in. And then that never happened," recalls Laura, saying that while the people caring for her seemed to be in agreement about her treatment, she felt she "wasn't in the loop." Steve cautions, "If you don't say anything, doctors will think, 'Well, he understands everything I've told him,'" adding, "If you don't understand something—**you need to ask.**"

Ask yourself:

What are my most pressing concerns regarding my treatment at this time? Have I communicated these concerns to my doctor?

I am most concerned about...

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Is there anything about your illness, treatment plan or prognosis that you feel needs more explaining at this time?

What needs more explaining is...

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The role you wish to have in decisions about your care can vary from person to person and may change in different circumstances or points in time.

Fritz advises, "Inquire from time to time: **Is this what you want?**' 'Is this what we want?' Make sure the decision-making process is a shared one." "The patient should guide their life, not the doctor," says Rich, but "you've got to communicate to [doctors] what you want to do."

Ask yourself:

Am I satisfied with how involved I am in making decisions about my care? If you do not wish to be involved, do you feel comfortable that the doctors who are making those decisions fully understand your concerns and priorities?

At this time, my involvement in the decision making process is...

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I would prefer my involvement to be...

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In addition to your doctors what other resources have you found helpful in the decision making process?

When I need help in making decisions, I also look to...  
(examples: loved ones; a second opinion; the Internet; support groups; advocacy organizations, etc.)

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## Chapter 6 Understanding Your Choices

Understanding what is most important to you can help guide the decisions about your treatment and care options. Communicating your needs, preferences and goals makes it possible for your healthcare team and support network to understand the reasons for your decisions.

Fritz understands that the rewards of continuing treatment more than exceed the risks but that there are no guarantees. **He and his wife decide together** “to do whatever my physician thought was appropriate” to arrest the progress of his disease. Rich says that he decided the quality of his life was most important and that he was not going to “let the disease run his life.”

How one measures the overall effect of illness on their lives physically, emotionally, spiritually and in day-to-day functioning can differ from person to person.

Ask yourself:  
What determines my quality of life?

My quality of life is determined by...

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Fritz says, “You, in the end, need to **know what those choices are** and to make the ultimate choice yourself. But if you have people who know of your situation, they can advise you, they can assist you in making the decision...[which] in the long run is the right decision to make.”

Ask yourself:  
What concerns influence my treatment decisions?

The concerns that influence my treatment decisions are...

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Ask yourself:

Which people influence my treatment decisions the most? Are those people familiar with and understanding of my specific concerns?

The people who influence my treatment decisions are...

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Laura tells us, "There really weren't any good choices to make. There just was what there was to try." She says, "I know I'm tired of doing what I've been doing... but I don't want anybody to think that I 'gave up.' And I think I have that fear because **I have a choice to make.**"

Ask yourself:

Are any of my decisions being influenced by people who may *not* fully understand my concerns? If so, is this something that needs to be addressed?

The people who need to better understand my concerns are...

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## Chapter 7 Living With Uncertainty

“Incurable” does not mean “untreatable”—but it does place both doctor and patient in uncertain territory. Being honest about this uncertainty can strengthen the doctor-patient relationship and help your doctor provide whatever guidance he or she is able to, despite what is unknown.

Fritz asks, “How am I going to manage this? How are we going to manage this?” Steve admits, **“It’s a very difficult balancing act.”** Cathy says that when she began to speculate to her doctor about “how I was going to organize the rest of my life,” she discovered they had very different timeframes in mind.

“I knew my life was going to be shortened, so the things I wanted to do, I’d better hurry up and do while I could,” says Rich. “So many people put things off... but you don’t know what next year’s going to bring.”

Facing uncertainty, many patients find comfort in action.

Ask yourself:  
What would I like to do while I am still able?

While I am still able I want to...

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Ask yourself:  
What will I regret if I put things off?

I may regret...

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“My attitudes toward death have become more of a concern,” says Fritz, who hopes that he’ll **be better prepared and able to cope** with the uncertainties about the future if he allows some of the spirituality that he “always had but tended to repress to come forth.” Rich thinks it is important to believe in “something.”

Some people’s decisions about their care are influenced by their religion or spiritual beliefs. For others, this may not be the case.

Ask yourself:

What role, if any, do religion or spiritual beliefs have in how I approach my care?

My religion/spiritual beliefs influence...

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An uncertain future can produce worries and anxiety but it can also be an opportunity to summon up inner strengths and clarify priorities.

Ask yourself:

What are some of the ways I manage uncertainties about the future?

Facing uncertainty about the future I find myself...

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## Chapter 8 Courage to Talk About a Tough Subject

For many people death and dying is the most difficult subject to face and the hardest to talk about openly. And yet, if unspoken, how can we ensure that our wishes and healthcare choices—whatever they may be—will be respected? **Who opens the conversation and when?**

“I don’t think it’s ever going to stop being hard to talk about somebody dying,” says Laura. Rich admits, **“I worry about how long I really have.”** “I worry more about death,” says Fritz and quickly corrects himself, “I got it wrong, I worry more about dying than death.

Ask yourself:  
What worries me most about dying?

When I think about dying I worry about...

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Cathy says she knows she isn’t going to live as long as she’d once thought she would, and she wants people to know, **“I’m getting to be okay with that.”** “I don’t want to go through a lot of pain, a lot of suffering,” says Steve. “Because not only do you suffer, your family suffers. And I don’t want that for them.”

Ask yourself:  
To whom have I communicated my wishes and preferences about end-of-life care?

I have already talked to...

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I need to talk to...  
(examples: my doctor, nurse, family, friends, clergy)

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Ask yourself:

What if I am unable to speak for myself—who will speak for me?

The person who understands my wishes and will speak for me is...

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Note: **The best way to ensure that your wishes and concerns are known** to both your loved ones and your healthcare team is to complete a legal form known as an Advance Directive.\*An Advance Directive puts in writing your preferences concerning medical interventions and end-of-life care. It also allows you to designate someone to make decisions for you under the circumstances you specify.

It is our hope that the workbook will help open conversations with loved ones and healthcare providers about your preferences for end-of-life care sooner rather than later and serve as an aid for completing your Advance Directive.

\*[http://www.vtethicsnetwork.org/forms/advance\\_directive\\_short\\_form.pdf](http://www.vtethicsnetwork.org/forms/advance_directive_short_form.pdf)



## Chapter 9 What I Hope For

Patients' hopes vary from individual to individual and can change over time. What you hope for may have to do with your health, but your hopes may also be about your other life goals and personal milestones.

Rich and Cathy share the hope that when the treatments they've been trying are no longer working, there will be new drugs to try. "But I'm really thankful for all the blessings we've had in our family," says Rich.

"I hope that whatever happens, people understand why I made whatever decisions I made," says Laura. "And **I hope somehow there's a way to make it easier.**" Steve hopes he'll be able to face the end of his life still possessing "a degree of who I am now."

Hope is personal; it can mean different things to different people.

Ask yourself:  
What do I hope for today?

At this time I hope...

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“I have a limited period of time—by most definitions, a short period of time, before things go into a decline,” says Fritz. **“I want to make those days, weeks, months, years as pleasurable, meaningful, and rewarding as I can.** That’s what I hope for.”

Hope and reality can be experienced at the same time.

Ask yourself:

What if the treatments were no longer working, what would I hope for?

If the treatments were no longer working I would hope...

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Ask yourself:

How do I hope to be remembered by those I love and respect?

I hope to be remembered as...

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## A GLOSSARY OF MEDICAL TERMS

Illness is a world with its own language and the terms themselves may not have the same meaning for both patient and doctor. We have created this glossary as a guide to help patients talk to their doctors and nurses about the meaning of terms.

**Treatable:** possible to treat; responsive to treatment

**Curable:** being such that cure is possible

**Cure:** to make an illness or injury go away

**Curative Treatment:** treatment aimed at producing a cure

**Diagnosis:** identifying a disease by its signs or symptoms, and by using imaging tests and lab findings

**Hospice:** a special kind of care for people in the final phase of illness, which is also available to families and caregivers. The care usually takes place in a patient's home or in a home-like facility.

**Malignant:** cancerous; dangerous or likely to cause death if untreated; a mass of cancer cells that may invade nearby tissues or spread to distant areas of the body

**Metastasis:** cancer cells that have spread to one or more sites elsewhere in the body. The plural of this word is metastases.

**Metastatic:** a way to describe cancer that has spread from where it started to other parts of the body

**Mutation:** a change in the DNA of a cell

**Palliative:** treatment that relieves symptoms, such as pain, but is not expected to cure disease. Its main purpose is to improve the patient's quality of life. Sometimes chemotherapy and radiation are used this way.

**Prognosis:** a prediction of the course of the disease; the outlook for the chances of survival

**Quality of Life:** overall enjoyment of life, which includes a person's sense of well-being and the ability to do the things that are important to him or her.

**Recurrence:** the return of cancer after treatment.

**Response:** outcome after treatment, or the reaction to drug or any other therapy



## **About the SpeakSooner Initiative**

**SpeakSooner, an initiative of the Bennington, VT-based Center for Communication in Medicine (CCM), is committed to getting patients facing serious illness, their families and healthcare professionals on the same page.** Our programs support timely and frank conversations that weigh the risks and benefits of treatment options, including palliative and hospice care. While other projects offer more narrowly focused decision-making aids we emphasize communication about emotional, spiritual and relationship issues that coincide with and can influence treatment choices.

Through the SpeakSooner Initiative we hope to **empower patients to actively engage in decisions about treatment; help caregivers articulate needs and secure support; and engage healthcare professionals to honestly and compassionately communicate about prognosis, treatment options and quality of life issues.**

Fifteen years of fieldwork in medical practices provided CCM founders Dr. Bernard Bandman, Celia Engel Bandman and the late Patricia Barr the opportunity to grasp the many challenges of communication between patients, their families and healthcare professionals. We observed that medicine is a world with its own language where time is at a premium. Many of the efforts to improve communication have focused on healthcare professionals but patients often find themselves unprepared to be effective communicators. Consultation with medical and patient/family advisory groups informed the creation of our *Difficult Conversations Toolkit* to help guide patients to think through their goals, be prepared to advocate for themselves and invite doctors to be open and honest in discussing prognosis, treatment options and quality of life concerns.

In 2013, building on the knowledge gained in the field, the Center for Communication in Medicine launched the SpeakSooner Initiative. The project combines our patient-centered *Difficult Conversations* materials with communication skills training for healthcare professionals and community-based programs to educate the public about the key role of communication in improving healthcare delivery.

**If you would like to learn more about the SpeakSooner Initiative or support our work please visit [www.SpeakSooner.org](http://www.SpeakSooner.org)**

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During the process of editing and revising the workbook for use in clinical practice, we looked to our medical advisory group for their thoughts and suggestions.

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