SpeakSooner®

A PATIENT'S GUIDE TO DIFFICULT CONVERSATIONS

CENTER FOR COMMUNICATION IN MEDICINE®

HOW TO USE THIS GUIDE

This Guide is designed to help patients identify their own questions and concerns so they can prepare to communicate clearly and openly with their healthcare team, family and friends.

Each chapter has questions that help you to think about your concerns when facing serious illness. Your answers can be useful in communicating with family and healthcare providers.

Move through the chapters at your own pace and use a notebook to record your thoughts.

You can also work online at speaksooner.org. The online version includes video interviews with patients. A secure login saves your work.

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Understanding Your Prognosis

Many patients feel uncertain about what their prognosis actually means, even after speaking to their doctors.

"It's not curable but it's treatable. That was hard to hear."

Cathy

QUESTIONS:

What do you remember your doctor saying about your prognosis?

What does it mean? Is it treatable? Is it curable?

What are your questions?

prognosis
the likely course of a disease or ailment

Coping With Unwelcome News

No two people will react the same way to a serious illness. Some people want more information — others may prefer less.

QUESTIONS:

How are you dealing with unwelcome news?

What are you doing to cope?

Is what you are doing helpful?

Are you saying what you feel?

Who needs to know?

Speaking With Family & Friends

Friends and family may not understand exactly what you are going through and may be having their own questions and concerns about your illness – wishing to help but not knowing what kind of help you need.

QUESTIONS:

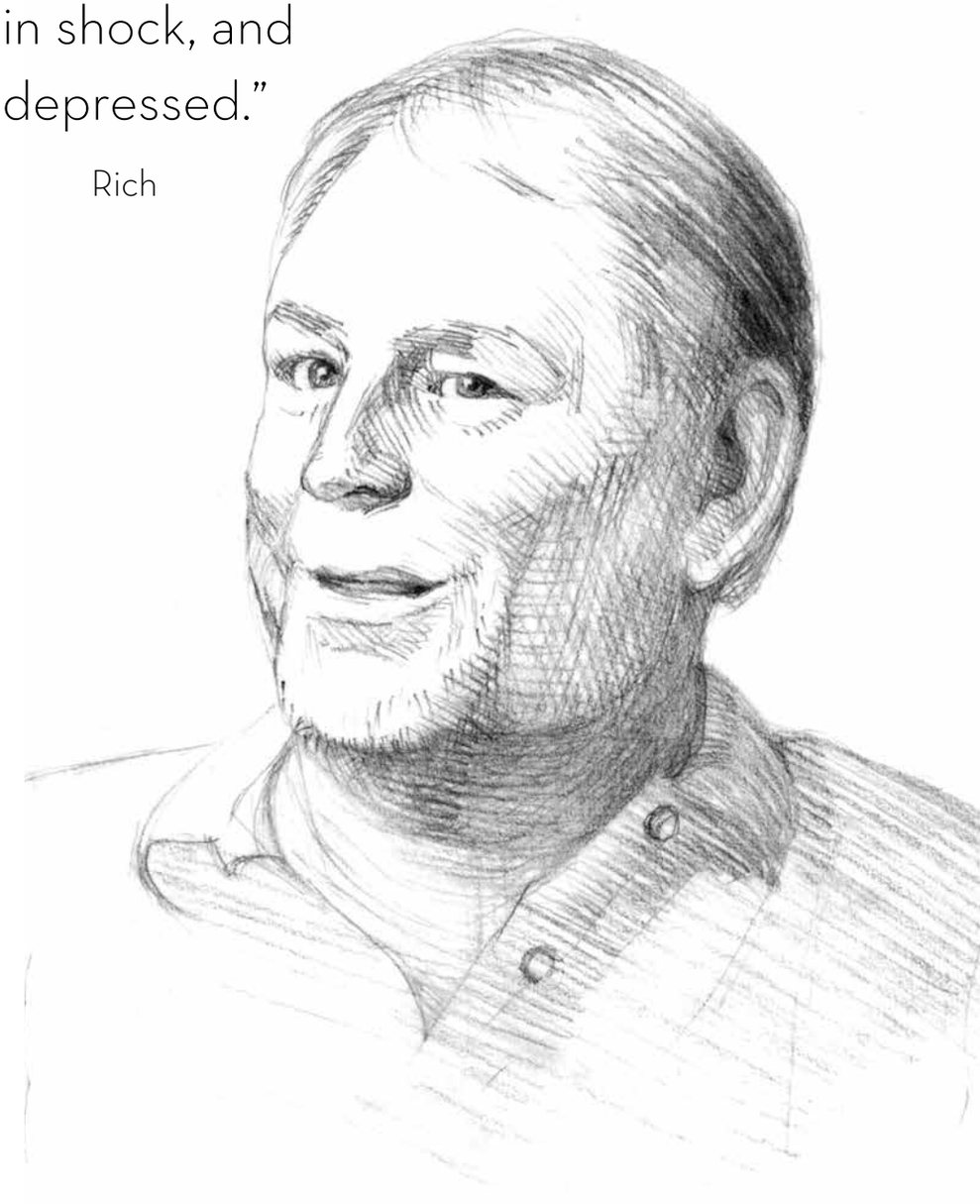
Are you avoiding sharing this news?

What do you need from family? From friends?

Who are you trying to protect?

"No question, you're gonna be in shock, and depressed."

Rich



What You Need From Your Healthcare Team

Over time your goals for care can change –

and so can what you need from your healthcare team.

QUESTIONS:

What do you need from your doctor/healthcare team?

Are you using complimentary therapies? (acupuncture, meditation, supplements)

Have you communicated this to your providers?

What are your questions?

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.

"How am I going to manage this?"

QUESTIONS:

What are your concerns about treatment?

Have you asked your providers about them?

What needs more explanation? Are you taking an active role in decisions about your own care?

Whose in charge of your care?

What are your most pressing concerns?

CHAPTER 6

Understanding Your Choices

Communicating your needs, preferences and goals makes it possible for your providers and support network to understand the reasons for your decisions.

QUESTIONS:

What defines quality of life for you?

What influences your treatment decisions?

Who is influencing your decisions?

Do they understand your concerns?

Have you shared your concerns?

"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."

Laura

Living With Uncertainty

"Incurable" does not mean "untreatable"
– but it does place both doctor and patient in uncertain territory.

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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.

QUESTIONS:

What would you like to do while you are still able?

Do your religious or spiritual beliefs affect your choices?

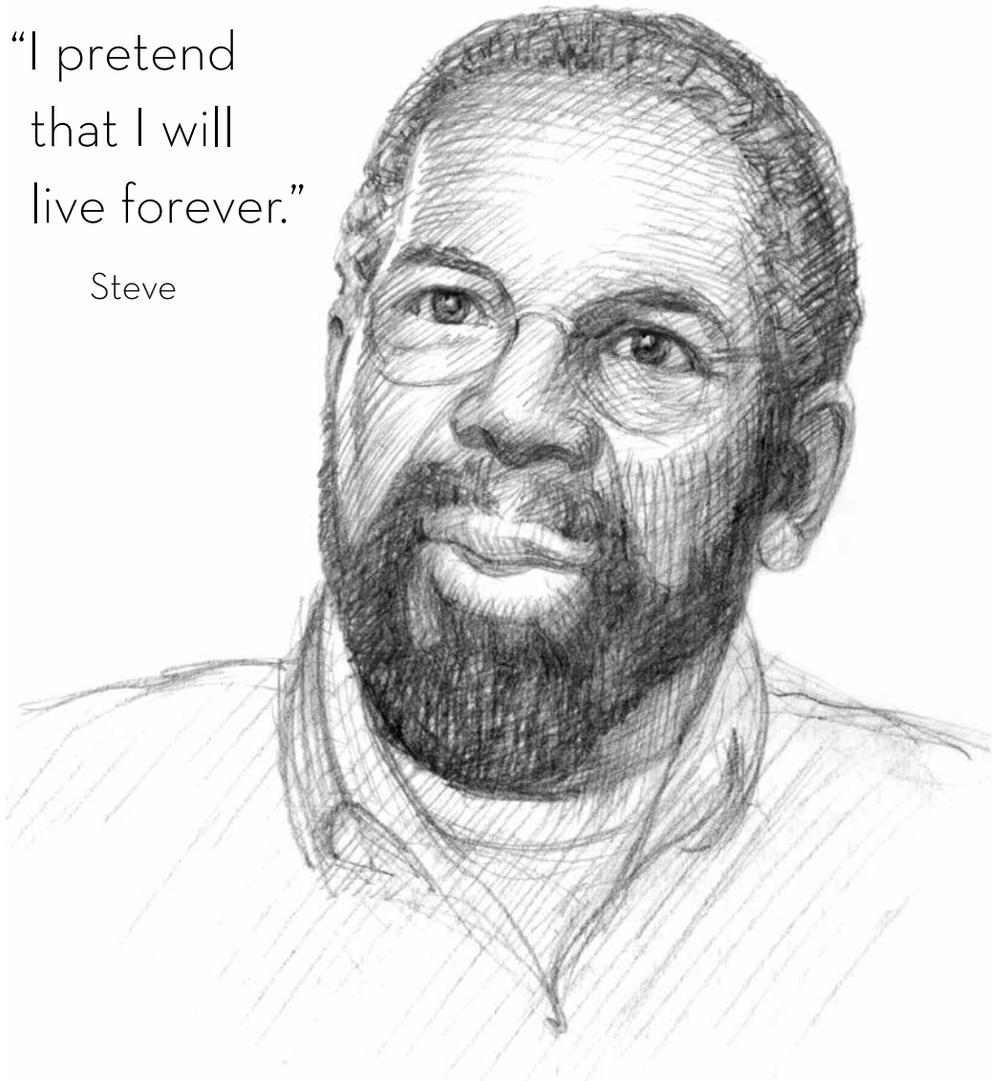
What will you regret if you put it off?

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.

"I pretend that I will live forever."

Steve



QUESTIONS:

Have you communicated your preferences for end of life care?

Have you completed an advance directive?

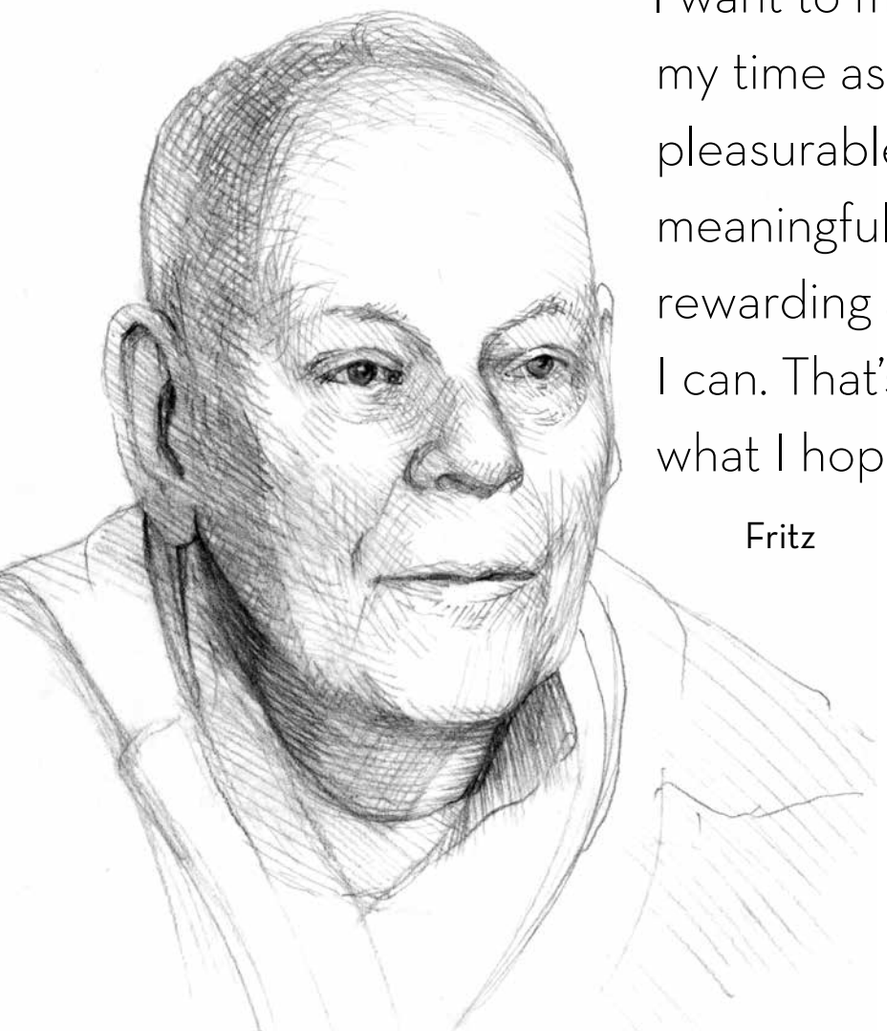
Who do you need to talk to about your preferences in end of life care?

What worries you most about dying?

What I Hope For

The hopes of patients vary from individual to individual and can change over time.

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



"I want to make my time as pleasurable, meaningful, and rewarding as I can. That's what I hope for."

Fritz

QUESTIONS:

What do you hope for?

If treatment is no longer working, what would you hope for?

How are you planning to fulfill your hopes?

SpeakSooner®
good communication is good medicine®
a center for communication in medicine initiative

SpeakSooner® is a Center for Communication in Medicine® (CCM) initiative that offers educational programs and tools to promote open and honest communication between patients, families and healthcare providers – sooner in the course of illness.

Since 2001, CCM's programs have helped patients to prepare for conversations with doctors about treatment options, quality of life considerations and supportive care needs, leading to decisions about care that align with one's values, preferences and goals.

The Center for Communication in Medicine is the education division of the Institute of Medical Humanism, a Bennington, VT based nonprofit organization.

WHO WE ARE

BERNARD BANDMAN, PhD

Dr. Bandman established the psychological services program at Southwestern Vermont Regional Cancer Center in Bennington, VT. He is a founder and Executive Director of the Center for Communication in Medicine. Dr. Bandman has been featured on Vermont Public Radio, NPR and appears in Dana Farber Cancer Institute's Living Beyond Cancer video library. He is co-author of this Guide.

CELIA ENGEL BANDMAN

Ms. Bandman created and implemented the role of medical humanist at Southwestern Vermont Regional Cancer Center in Bennington, VT. Her pioneering work inspired the creation of this Guide, of which she is co-author. Ms. Bandman is a founder of the Center for Communication in Medicine. Her articles have been published in the Journal of the American Medical Association, Journal of Clinical Oncology, Journal of Supportive Oncology and the Journal of Cancer Education. Read her blog at speaksooner.org.

You can help us expand our reach!
Make a donation at
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Design: Leslie Noyes Creative Consulting | Portraits: Stella Ehrich | Illustrations: Lindy Borden
Photography: Nicole Sauer Photography, unless otherwise noted

"Every patient and every social worker, nurse, doctor and chaplain should offer the Guide as part of saying to a patient and family: 'I'm here; we can talk; I'll listen; your journey is important to me.'"

Linda Emanuel, MD, PhD,
Northwestern Feinberg School of Medicine

"This Guide is giving me the opportunity to ask myself questions that I assumed I had thought about adequately."

Susan H., patient

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