



What Can I Say?

A GUIDE TO VISITING
FRIENDS AND FAMILY
WHO ARE ILL

Simon and Karen Fox

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What Can I Say?:



Rotary Club of Santa Barbara

All proceeds from the sale of this book help to fund the *Adventures in Caring* volunteer programs in hospitals and nursing homes. These programs help patients and families cope with the loneliness and emotional distress of illness, injury and death. The *Adventures in Caring Foundation* is a nonprofit, human service organization, dedicated to teaching and delivering compassion.

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Introduction

It's not easy to be with a person you care about when he or she is suffering from an illness and in pain. You may have asked yourself: What can I possibly say that will bring comfort at such a time?

Lacking words, friends and family members often stand back, leaving the care to the doctors, the nurses, and the wonders of modern medicine. Unfortunately, in that silence, the person who is suffering can feel terribly alone.

People who are sick—whether hospitalized, in a convalescent home, or at their own home—have a tremendous need to know that someone cares. A visit from a friend or a relative can ease the agony of being alone and in pain, and bring hope, joy, and peace where before there was none. Your caring presence, with or without words, can be the gift that heals.



ABOUT THE AUTHORS

Karen and Simon Fox know the difference it makes to bring kindness and



*“Those who bring sunshine to
the lives of others cannot keep it
from themselves.”*

—James Matthew Barrie

compassion to people who are ill. Together, this husband-and-wife team from Santa Barbara, California, have been involved for over 17 years in developing new kinds of patient care programs to deliver psychosocial support to people who are sick, lonely, or dying. Karen Fox is a cancer survivor with more than 30 years of experience assisting patients and their families, both as a health care professional and as a volunteer. Simon Fox is a former physicist with 25 years of experience in designing volunteer and adult education programs.

In 1985, Karen created the *Adventures in Caring Foundation*, a nonprofit organization dedicated to alleviating the emotional distress and loneliness that often accompany a serious illness or injury. Awarded a *Point of Light* by President George Bush in 1991, *Adventures in Caring* is best known for the Raggedy Ann & Andy Visiting Program, which lifts the spirits of patients and their families in 32 hospitals and nursing homes in California and other states, every week, all year round.

Dressing up as the characters Raggedy Ann and Raggedy Andy from the childhood storybooks and visiting those who are confined to bed or a wheelchair, volunteers provide a safe, non-threatening space for patients to feel accepted and talk about their experience. The Raggedys mostly listen, offering people

who are alone and afraid the healing confirmation that someone cares. Karen chose the characters of Raggedy Ann & Andy because they are symbols of kindness and unconditional love—the very things that we all reach for in a time of crisis.

There's a fine art to bringing hope, easing tension, and giving encouragement to people who are suffering and feeling alone. It's not so much the words you say as the love you put behind those words. Karen found this out when she first began to visit the sick and discovered the healing power of love, which today is the core of the *Adventures in Caring* training programs and services.

HOW KAREN BEGAN

One afternoon, in the fall of 1983, Karen Fox was at work when she received a phone call from her doctor's office. "Your tests are abnormal," she was told. Her mind and pulse began to race. Had the cancer returned? Devastated by the news, Karen glanced down to regain some composure, and there on her desk was a photograph on the back of a medical magazine. A little girl held the hand of a physician, and in her other hand was a doll—Raggedy Ann.

At that moment, Karen's boss, Dr. Nelson, walked in. Karen was still in a daze from the bad news, but

the photograph had stirred something deep—an alchemical instinct to turn the heavy metal of adversity into the gold of helping others.

“What do you think of this idea?” Karen asked. Dr. Nelson, a conservative physician in his seventies, gave her an unsuspecting ear. “What if I dressed up as Raggedy Ann, and visited the patients across the street at Cottage Hospital on my lunch hour?”

Karen had worked as a medical assistant and administrator for Dr. Nelson for 15 years, and he knew her well. She was reserved and as far as he knew, had never dressed up in a costume in her life, not even on Halloween. Managing to conceal his surprise, he simply asked, “Well, what is your intention?”

“If I’m invited into the rooms of some patients,” Karen responded, “my hope is that I could lift their spirits, their hearts might open, and they would know that someone cared.”

“I think it’s a great idea,” said Dr. Nelson, “Why don’t you call Cottage Hospital right now and see when you can get started?”

With those words of encouragement, Karen made the call and so began her adventure. Cutting through red tape took almost six months, but finally, around Valentine’s Day, 1984, with her knees knocking inside her striped bloomers, Karen took her first

steps as Raggedy Ann across Bath Street and onto the patient floor of Cottage Hospital.

The very first person she visited had throat cancer , and couldn't speak. His two sisters, who invited Raggedy Ann to see him, explained that their brother hadn't spoken for eight months. "Would you please come in and say hello?" they asked. "Maybe your bright smile will cheer him up." Karen agreed, took a deep breath, and entering the room, approached the bed of the sick man.

"Hi, it's Raggedy Ann," she whispered, not wanting to wake him if he were sleeping. "Would you like a visitor today?" Looking up to see if he had heard correctly, he began to smile and nodded his consent. Karen told him that this was her first day volunteering as Raggedy Ann, and she was nervous. She hoped that this visit with him would give her the courage to continue. Then, with a full heart, and at a loss for other words, she said to him. "I love you." His eyes gleamed and a tear rolled down his cheek. Even without speaking, a connection had been made.

As Karen walked out of the room into the corridor, she heard a faint, gravelly voice call out to her from inside the room, "I love you too, Raggedy Ann!" Stopped in her tracks and deeply moved by the voice of a man without one, she paused for a moment, felt the love, and quietly wept. Karen knew this was a

confirmation that she was on the right path. “Well, you’ve got me now, God,” she prayed.

Humbled and in awe of the healing power her visit had demonstrated, Karen vowed to continue her mission. Some 20 years later, having triumphed over her own battle with cancer, Karen Fox is still bringing the gift of compassionate communication to people in need by training and supporting a whole cadre of Raggedy Anns and Andys to carry on what she so bravely began.

To date, the Raggedy Ann and Andy team has made over 750,000 heart-to-heart visits with hospital patients and their families, providing vast knowledge about interacting compassionately with people who are ill. As a result, the Foxes’ training methods in the art of communicating with compassion are now being used by over 3,000 organizations nationwide to teach health care staff, students, and volunteers.

It is from their wealth of experience that Karen and Simon Fox wish to share with you some practical information on what you can say and do—and, more important, how you can *be*—when visiting friends and loved ones who are sick and in need of your love and support.





*“It is only with the heart that
one can see rightly; what is essential
is invisible to the eye.”*

—Antoine de Saint-Exupéry



Giving the Gift of Compassion 1

Visiting the sick and expressing your compassion for another person's suffering is an art, not a science. There is no formula you can mechanically apply . There is no such thing as “the proper thing” to automatically say, to make a person feel better . Rather, compassion is a way of being that is expressed through four very fundamental elements. These four elements of compassion are:

- 🌿 Attention
- 🌿 Acknowledgement
- 🌿 Affection
- 🌿 Acceptance

The four elements of compassion are not just four things you can do. They also correspond to four basic needs which every human being has. When you meet these needs, your presence is beneficial and appreciated.

People who are sick are especially in need of the care that is expressed through *attention, acknowledgement, affection* and *acceptance*. Carefully paying attention helps people feel heard. Acknowledgment helps people feel respected and appreciated. Affection helps people feel connected. Acceptance helps people feel safe. When you are focused on meeting these needs for a sick friend or relative, you naturally discover what to do and say , making your visit a valued contribution.

In her mission as Raggedy Ann, Karen practiced the four elements of compassion by bringing them into her interactions with patients she visited, as demonstrated by the following story told in her own voice:

KNOWING THAT SOMEONE CARES

“Susan has been crying for two days straight,” said the nurse. “I’m concerned that the depression is interfering with her recovery—and there’s nothing more we can do for her medically. Karen, would you go in and visit with her? Maybe you can lift her spirits.” I took a deep breath and accepted the challenge.

Before entering the patient’s room I knocked gently on her door. “Is it alright if I come and visit with you for a few minutes?” I asked. Between the sobbing, I heard a faint “Okay .” Knowing the situation was

sensitive, I made a special effort to bring my full attention to understanding Susan's experience.

Susan was doubled over , crying into her pillow , Kleenex boxes strewn around the bed. By her body language and the tension in her voice, I could tell Susan was not just depressed, but actually quite frightened.

After a pause, I asked, "Would you like me to sit here with you?" Then, following my intuition, I asked, "Would you like me to hold you while you cry?" Susan reached out her thin, pale arms and fell into my embrace. I held her until the tears stopped.

Susan began to talk, and I learned that she was a single mother with no family and no income. She was worried that because of her illness she couldn't care for her small child, and he would be taken from her and placed in a foster home. Susan was so afraid of not getting well, she was making her condition worse.

As we talked, her confidence grew . I listened attentively and let her guide the conversation, giving her a chance to talk freely about what was on her mind without interruption or fear of judgment. I looked into her eyes as we held hands and together shed a few tears.

A few days later, I met Susan again, this time in the hospital elevator, an I.V. pole in her hand. "Your visit made all the difference," she said, beaming. "Now I



*“Talk not of wasted affection;
affection never was wasted.”*

—Henry Wadsworth Longfellow

think I can cope. I just needed to know that someone cared about me. Thank you for making me feel wanted.”

As I passed by the nurse’s station on my way to another visit, the nurse who’d been concerned for Susan’s recovery smiled at me and said, “It’s really amazing what a good listener can do for someone, after we’ve done all we could medically. Susan is recovering today because you cared to listen. Thank you.”

PRACTICING THE FOUR ELEMENTS OF COMPASSION

If you bring the elements of *attention*, *acknowledgement*, *affection* and *acceptance* to all your actions and words, you will be giving the gift of compassion.

When you practice these core elements of compassion, your heart naturally opens and you gain creativity and skill in knowing how to communicate what you feel.

Attention. This element involves being aware of the signs, signals and clues that indicate what is important to others. Listen, look, feel and notice are your key directives for giving attention. Let go of your own personal concerns, worries and cares, and focus entirely on the experience of the person you are visiting. What are they telling you about what is important to them, either verbally or by their body

language? As simple as it may sound, just being with another person in this way is an expression of love.

Too often, visitors will pay attention only to what's wrong with the sick person. That's the doctor's job. Your job is to focus on what's right with the person, and to find out what may be of deepest value to him or her.

You can focus your attention on the person's courage, spirit, memories, and mannerisms, letting him or her tell you whatever is of interest to talk about in the moment. Every person has a unique background, spiritual outlook, and state of mind. The key is to become genuinely interested and open to the person as an individual, not merely as someone who is sick and in need.

Karen sincerely wanted to understand what Susan was feeling and why. Genuine interest gave Karen eyes to see that Susan was not only depressed but also afraid. By giving Susan her full attention, Karen opened the door so Susan could talk about what she wanted to talk about, giving words to the feelings that were overwhelming her. Without keeping her attention solely on Susan, Karen would have missed the clues that enabled both to communicate and connect so deeply.

An illness can be a tragedy, and it can be a turning point. It is often an opportunity for two souls to meet. Whether you have just met the person or you have

been together for a lifetime, don't assume you know everything about him or her. Illness brings up new issues and new perspectives. If you look for the good, the beauty, the strength and the wisdom, you will find it. All it takes is your full and generous attention.

Acknowledgement. Once you have given your full attention to your sick friend or relative, fully hearing what he or she may have to say you can acknowledge the person's experience and recognize what is special about them. Acknowledgement means expressing your respect and appreciation for a person as a unique individual.

All of us, especially when we are sick, need to know that others recognize our existence. So often visitors talk about sick friends and relatives as if they weren't really there, ignoring their very existence and leaving them to feel invalidated or worse, like helpless victims. Express your recognition by speaking directly to the person who is sick, engaging him or her in a life-affirming conversation that leave that person feeling encouraged and empowered.

When you put into words your awareness of someone's strengths, unique abilities, heartfelt longings, you help to preserve that person's dignity and bolster a desire to live and recover. You can also impact the course of their illness for the better. The latest scientific research shows that animals and people get well when



*“Of one thing I am certain, the body
is not the measure of healing—
peace is the measure.”*

—George Meltom

they are treated specially and made to feel worthy . You fulfill this need when you pay a compliment, appreciate uniqueness, or remind someone just how important he or she is to you and to others.

You can acknowledge people through your spoken words, but also through your body language. A smile, moving closer , making eye contact—all of these show that you are interested. A twinkle in the eye, or a tear , a glance that says you care. Karen acknowledged Susan's need to be held and comforted, letting her know that fundamentally whatever she was experiencing was valid and important.

One of the most powerful forms of acknowledgement is listening and then asking questions that allow people to speak freely about what is important to them. By listening to Susan, Karen affirmed that Susan's concerns were valued and worthwhile, and let her know she was cared for and wanted. Acknowledgement is powerful medicine, lifting a person's sense of self-worth and courage when otherwise he or she might feel useless and afraid.

Affection. Affection is the element of human touch, warmth and caring. Kind and gentle touch is the cornerstone of a good visit.

In the high-tech world of modern medicine, with its emphasis on procedures and instruments, patients are often left hungry for the expression of touch and

caring. You can express kindness through touch: holding hands, giving a hug, a kiss, or holding someone in your arms. These simple gestures, so well-received by people who may feel alone and afraid in an institutional environment, can make the difference in them feeling comforted and cared for.

If it seems appropriate, offer a foot rub, a hand rub, or a shoulder massage to relieve the tension that may have accumulated from an extended bed stay. Don't worry about doing it right. People who are seriously ill don't need you to be an expert—they need your love.

Be aware that people from different cultures and backgrounds, and people in pain, respond to affection in different ways. Make sure you notice what kind of affection suits a person best. Remember that elderly patients are usually very fragile and their skin can bruise easily—so be gentle, tender and assuring.

Most of all, let your positive emotions guide you and follow your heart. Show your affection in a way that you know will be appreciated. A smile is something that everyone understands. Hugs, waves, holding hands—all add warmth. Allow yourself to be personal, warm and spontaneous, even humorous and light at moments. Karen trusted herself to let Susan embrace her, and to hold Susan's hands as Susan talked and wept. Follow your intuition about what kind of

physical comfort may be appropriate and helpful for a person.

Acceptance. Acceptance is expressed when you are being non-judgmental, tolerant, and forgiving. It means allowing a person to be just as they are—and just as they aren't.

Acceptance provides a safe zone in which people can talk freely about their hopes and fears, without the fear of being judged. Acceptance frees people to share their true feelings, to talk about difficult issues. It gives them a chance to talk honestly and openly—a rare opportunity for most of us.

Karen allowed Susan to cry and talk about what was worrying her without giving her advice or offering her pity. Karen accepted Susan and did not compare her to others, or try to take away her suffering. She did not try to fix or rescue her. By simply accepting exactly what Susan was experiencing, Karen opened the space for Susan to feel safe, loved and wanted so she could begin to heal.

Acceptance can be misunderstood as giving up on someone when there is nothing we can do to change things. But acceptance need not be resignation in the face of change. When you accept that what is, *is*—meaning you cannot control it—there is the possibility of serenity and peace. From peace comes freedom and hope. When people are sick, they need more than

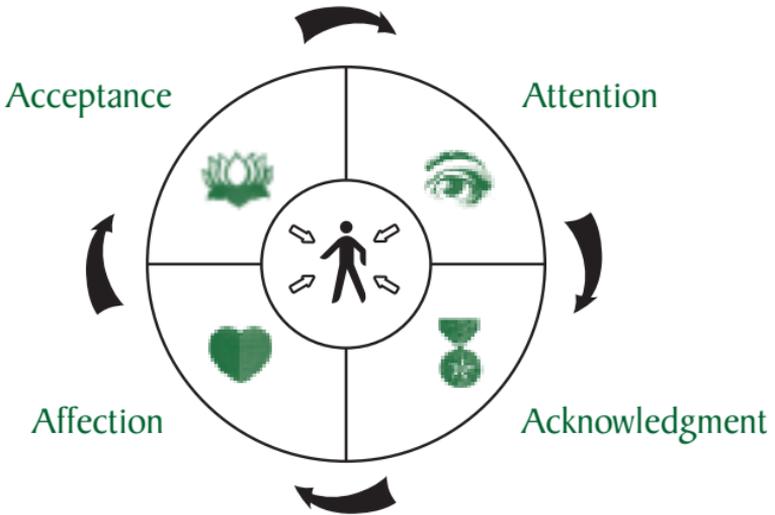
ever to know that you accept them and accept their condition, because it gives them freedom to let go and trust. Sometimes letting go and simply accepting what had seemed frightening and hopeless is the turning point that brings about a change towards health.

Acceptance has a healing power. It allows emotions to flow and change. Emotions can be thought of as *e-motions*: energy in motion. When emotions are shut down or frozen, there is less energy available for healing, and illness can be prolonged. When people feel safe enough to share their deepest feelings, emotions begin to flow, change, resolve—and to bring healing energy. The latest medical research shows that freely expressed emotions and physical health often go hand in hand.

Remember to include these four elements of compassion in your interactions when visiting people who are ill. In summary, these are:

1. **Attention:** Be aware of the signs, signals and clues that indicate what is important to someone.
2. **Acknowledgment:** Let people know you recognize and appreciate them for their uniqueness as individuals.
3. **Affection:** Give the human touch of warmth, comfort, humor and kindness.
4. **Acceptance:** Allow people and conditions to be the way they are, without giving up.

Circle of Compassion



Putting it all together

The four elements of compassion are not a checklist of things to do one after another. Instead, they all come together to form a circle. As the conversation revolves around what is important to the person who is ill, they are sprinkled in whenever appropriate: a little closer attention here, a little more affection there... nourishing the soul in an an hour of need.

*“Our task must be to free ourselves . . .
by widening our circle of compassion ”*

—Albert Einstein



“The value of compassion cannot be over-emphasized. No greater burden can be borne by an individual than to know no one cares or understands.”

—Arthur H. Stainback