

PART

ONE

*Diagnosis
and
Treatment*

CHAPTER

1

You Are Not Alone

*We're born alone, we live alone, we die alone.
Only through our love and friendship
can we create the illusion for the moment that we're not alone.*
—ORSON WELLES

*It's often just enough to be with someone.
I don't need to touch them. Not even talk.
A feeling passes between you both. You're not alone.*
—MARILYN MONROE

Feeling *alone* is far worse than having cancer.

This is what many survivors told me, and what I instinctively know myself.

Most of the time I am very satisfied, even ecstatic, with my life as an independent, single woman. My lifestyle allows me to do the things I want to do when I want to do them. If I feel like staying in bed all day on a cold, rainy Sunday afternoon reading a book, I can do it. When I want to jump in my car or hop on a plane for a fun weekend get-away, only my budget might prevent me. I don't have to pick up someone else's dirty socks or put the toilet seat down constantly or put up with annoying in-laws. I can go

wherever I want on vacation, spend holidays with my family, and paint the living room any color I like. There are no demands from a partner or children that get in the way of my needs. I feel lucky to live in a time and culture that allows me the freedom to live independently, and I make the most of that freedom to live the kind of life that I want to live.

Most days, being single is pretty OK if not downright great. But when things are at their worst, when I'm sick or struggling with a household problem, or just having a garden variety bad day, I feel really alone because I don't have a partner to help out or comfort me. I think: I will always be alone, and I will have only myself to rely on. I fantasize about how much easier it would be if I had a partner. Financial hardship wouldn't be so bad with another income to fall back on. Health scares would be easier with someone there to hold my hand or give me a hug.

One 29-year-old female survivor said, "I've always hated how society makes such a big deal about being single, like it's so pathetic how your self-worth is tied to that. I never felt that way, aside from occasional loneliness, I could function just fine and was happy," she said. "Getting cancer was another story, though. Without a strong support network, it was difficult, and I had to admit for the first time that my single status was a detriment."

Another survey participant volunteered, "I realized how alone I was when hit with such a serious life event. My siblings and parents are half-way across the country, and my friends all work, so they weren't always available."

I know that not all partnerships are happy all the time, and that many a serious diagnosis has also been followed soon thereafter by breakup or divorce. I also know it is better to be single than to be in a relationship where I don't feel supported or cared for. Intellectually, I know that the grass is not always greener, but sometimes it feels like it is.

I assume that dealing with cancer would be more endurable with someone who loves me by my side—someone to hold me in the middle of the night when I'm afraid; someone to be there for every doctor appointment and procedure; someone to tell me it's going to be OK when it just doesn't seem like it ever will again. Married friends who have been diagnosed or even those who have dealt with a serious health issue or accident have marveled at how I did it on my own.

Other single survivors who were surveyed expressed similar feelings. "What was most lacking for me was companionship. I went to treatment and doctors alone, and it was hard to remember all the important information and lonely being surrounded by others who were there with loved ones."

Another shared, "The loneliness was sometimes unbearable. Friends help some, but it's not the same as having a partner." Someone else offered,

“I often felt alone during treatment—for a significant other, that is. It’s hard to admit, but after an experience like that, I often worry that I will not find a person that I could spend my life with and that it could be too late.”

Of course everyone goes through cancer alone. No one else can ever really understand what the experience is like, and it’s unique for each person. But as a single person, I’ve felt a special type of alone: devastatingly alone. There is so much to learn, so much to do and so many decisions to make about doctors, treatment options, financial considerations, and it can feel so overwhelming to make those by myself. It is one thing to have lots of great friends to support you (and I am lucky that I do), but it’s not a substitute for having one person who loves you unconditionally by your side.

“I felt so lonely,” said one survey participant. “Friends and family can’t understand what you are going through and aren’t there when you have insomnia and the loneliness hits hard. It would be nice if there were support groups for single young people.”

Another added, “Nights were the hardest. It was the time I was left alone with my thoughts, which were tough to deal with.”

When I spiral, my friends remind me that I may not have a partner but I am not alone. I am part of a community that cares for me, and friends and family have always provided support when I needed it. Within the first hour of my most recent health crisis, three people in my life dropped what they were doing to come to my aid. Those loving relationships are just as important and essential as any committed partner, yet my feeling of aloneness often persists. Through my survey, I’ve realized this is common for single cancer survivors. Nearly 80 percent of the 100 single cancer survivors I interviewed reported feeling alone, and 77 percent cited connections with other cancer survivors as a top need.

Survey participants shared the following thoughts:

“Feeling isolated with my illness fed depression, which just made everything worse.”



“Feeling alone sucked. I had no one my age who could relate to what I was going through.”



“Even though I have a large support network, being without a partner was hard when it came to making treatment decisions. The night time is the toughest to be alone.”



The idea that if you haven't found "the one" then you are missing the only thing that really matters is also common. As one woman said, "I often don't feel I have much to live and fight for. So many times you hear people battling cancer say things like, 'If it weren't for wanting to be with my spouse, I don't know how I could have done it all.' Or people want to survive to be there for their children. If my life ended, it wouldn't really be a big deal to anyone but my mom, so motivation is pretty hard to come by when you're faced with side effects, stress, anxiety, bad news, uncomfortable tests, horrid procedures, putting your life on hold, debt and never having any time or money or energy. And all for what?"

When do you feel most alone?

With whom can you share what you are going through?

What makes you feel the most connected to others?

The Importance of Connection

Since you cannot do good to all, you are to pay special attention to those who, by the accidents of time, or place, or circumstances, are brought into closer connection with you.

—SAINT AUGUSTINE

I've had moments when I've thought about somebody, picked up the phone to call them and they are on the line already, and I think that maybe there's some vibration, some connection.

—CLINT EASTWOOD

Feeling alone is one of the most destructive emotions we can have. Research has shown that loneliness can impact stress, health, and immunity. According to Dr. Dean Ornish in his book *Love & Survival*, "Our survival depends on the healing power of love, intimacy, and relationships." When we lack those connections, we suffer. He cites numerous studies about the key role played by family, friends, spouses, and social connections such as church/synagogue or other community associations in fighting illness. Lissa Rankin, MD, cites some of the same studies as well as others in her book *Mind Over Medicine: Scientific Proof That You Can Heal Yourself*.

If you are single and battling cancer or some other illness, connecting with the people in your life, or finding new sources of support, may be one of the most important things you can do for yourself. Ask for what

Sources of Support

In a survey of 100 single survivors, these were the most common sources of support:

- 50 percent family (survivors cited them as really helpful)
- 37 percent friends
- 35 percent church community
- 31 percent coworkers (the latter three were cited as somewhat helpful)

Half of the participants cited that romantic partners barely acknowledged what they were going through and weren't a major source of support, though most were not serious relationships.

you need. Whether it's talking on the phone more regularly, going out for a walk, sharing coffee once a week, visiting or hosting a friend or sibling for a weekend, joining a support group, participating in group meditation or yoga classes, serving others directly, or any number of other things, do what you can to connect with the world around you.

It turns out that being single can be a predictor of shorter survival times and an increased chance of recurrence. And the studies don't just relate to cancer patients. In fact, Ornish's work is primarily with heart disease, but the findings suggest that even the common cold can be better protected against with quality social networks and interaction.

The most striking study cited was conducted by Dr. David Spiegel and colleagues at Stanford in 1989. Published in the British journal *The Lancet*, they studied women with metastatic breast cancer. Spiegel initially set out to prove that social connection did not have an impact on survival. Participants in the study were divided into two groups—both of which received the same conventional treatments such as chemotherapy, radiation, and surgery. One group also met together for 90 minutes each week over the course of a year to talk about the impact of the disease on their lives. They became comfortable enough to share their feelings openly, including fears of disfigurement, abandonment, and even death.

Five years later, Dr. Spiegel reviewed the data and was shocked to discover that women in the support group lived on average twice as long as the control group, and that all of the women in the group without support had since died. Dr. Spiegel wrote the book *Living Beyond Limits*

about the extraordinary findings of this study. Other studies have shown that support groups as short as six weeks long have had similar outcomes for the people who attended regularly. Each study controlled for diet, exercise, family history, and other factors that typically impact disease and found significant advantages to social connection even beyond these other factors.

Do the statistics mean that those of us who are single are doomed to get sick more often and die sooner than our married or partnered friends? Absolutely not! In fact, marriages with problems—a great deal of disagreement or stress—have been shown to produce negative effects as well. Support can come in many forms: a close network of friends with whom you can share your fears, a support group of other people who understand what you are going through, a close family, or strong ties to a religious or other community. No matter what form it takes, it requires a willingness to be vulnerable enough to truly open yourself up to others.

That last factor is perhaps the most difficult for many of us, and yet, the most important to truly offer authentic connection. It isn't the quantity of support that matters, but the quality. In other words, it's not the number of people who are there for you that counts, but how connected you feel with those who are around, and how much you can truly share what you are dealing with.

Sage Advice

From Sage Bolte, PhD, LCSW, OSW-C, oncology counselor and social worker

- Don't try to do it alone. Ask for help. People want to help and don't perceive it as a burden.
- Get creative to broaden your support system. Not just family, but also friends, church, or other survivors.
- Talk about your experiences both inside and outside of cancer.
- Work with a therapist if you find that cancer is defining who you are, rather than being a part of your story.

Dr. Bolte recommends four associations to help you find a qualified therapist. You can find these listed in the resources section under Counselors and Therapists.

Support Groups

Interestingly, more of the men I interviewed participated in support groups than women. Jeremie said about his medical team, “I was really impressed with the level of caring I received from my health care providers. I have a much greater appreciation for what they do. They were genuinely concerned and go above and beyond. I had no bad experiences throughout that whole thing.”

Jeremie was impressed by all the services provided by his cancer center in Minnesota as well, and found out about a support group from his surgeon. It meets once a month and is run by a nurse practitioner and a psychologist. He is the youngest guy in the group, but was happy to find two other guys there who were not only close to his age, but also recovering alcoholics like him. Having multiple things in common with other group members was important to him. It wasn’t just about cancer.

“I’m almost more proud of the fact that I didn’t get hooked on any of the drugs that I was put on during cancer treatment,” he said. “My addictive personality led me down this road again, so when the pain started to go away, I weaned myself off the drugs or I knew I would never get back to normal. One day I just threw it all out and that was that. Now I don’t even take Tylenol. That was a big turning point for me. It would have been easy to get drugs as a cancer patient.”

Jasan, a three-time cancer survivor, has attended a support group for young adults regularly for more than 10 years now. He read an article in the paper about the Bay Area group and felt compelled to go. Though he didn’t talk at all the first year, sharing only his name and diagnosis, he slowly became more comfortable. Finally being around a positive, safe environment helped, he said.

“I’m a typical dude that doesn’t want to talk about my feelings,” he said. “My mom would always try to get me to talk about it, but I never wanted to. Now I know there is freedom in talking about it. It really makes me feel good that I can help other people by sharing my own experience.”

The majority of single survivors I interviewed for this book did not report participation in a support group. Some of them, like me, found them to be more depressing than helpful, and couldn’t relate to the mostly elderly group members in far different stages of life. Those who found a group of people their age with similar issues and concerns, however, reported significant benefits.

How socially connected are you? What are some of the groups mentioned that you interact with regularly?

*What kind of support group or social network would appeal to you?
How might you find such a community?*

What are some ways you could connect more fully with your existing communities?

The book *Going Solo* suggests that singles who live in urban areas are actually more socially connected than their married counterparts, largely because the latter interact primarily with each other, while singles in cities get out more with others in social settings. This kind of connection with others, whether they have cancer or not, can also be beneficial.

Other factors that have been proven to influence healing and well-being according to Ornish:

- Roommates or living with family
- Pets
- Touch—massage, Reiki, or just holding the hand of a friend
- Community involvement and service
- Yoga and meditation (or other relaxation techniques)

Pets and Single Survivors

I have often heard the advice that if you are single, you should have a pet since they provide a motivation to get up in the morning, get home at a reasonable hour from work, and even help promote exercise, all in service to your pet's needs. Though my travel schedule and small condo have been deterrents for me in this area, I think it is great advice. I often say that while I don't have my own, I love other people's kids and pets.

Jeremie shared that although women have come and gone from his life, his dog is a constant source of companionship and love. "I am always hugging and squeezing her," he said. A beagle-blue tick mix, she was a stray that his ex-girlfriend just brought home one day. "No one knew where she came from," he said "but I don't know what I would have done without her. I honestly believe she is one of the loves of my life."

Susan felt the same way about her Great Dane who turned into a protector practically overnight when Susan was diagnosed with ovarian cancer. Kaya could sense when Susan was having physical problems. Adopted when she was just one year old, Susan's huge dog was destructive, nervous, and suffering from serious separation anxiety when she first came home.

In January of 2010, Susan had major surgery and received her diagnosis. She says almost immediately a new side of Kaya's personality emerged. When Susan came home following surgery, her four-legged friend was elated, but sensed a need to be gentle as she quietly sniffed Susan from head to toe.

"When she reached my incision area (a 12-inch vertical slash across my abdomen), she stopped sniffing and looked up at me with a worried expression," Susan said. "She was very sweet and gentle, which is saying a lot because she's a bit of a lug. Kaya is many things, but graceful is not one of them."

The day after arriving home from the hospital, Susan's friend came to stay with her to help with her recovery. As Susan moved from the couch to the bedroom, her friend got up to follow her and Kaya began to growl, backing the friend into a corner and not allowing her near Susan. "I was shocked," Susan said. "In the three years since I had adopted her, I had NEVER heard her growl."

Susan described typical Kaya behavior as: running for the hills at the sight of a bug, hiding in the bedroom when someone was at the front door, and snacking on the couch until it was unrecognizable. Susan went on to describe her laughter at the call from doggie day care once informing her that Kaya had to be moved to the small dog room because she was being bullied by a German Shepherd.

"I know it's weird (and inappropriate) to be proud about a dog growling at another person," Susan says, "but it felt good to know that she was protecting the 'injured' member of her pack, and the hockey player in me was happy to see her assert herself a little."

Kaya took her guardian role very seriously throughout Susan's recovery. When daily injections of blood thinner into Susan's stomach were required during the first week, and the shots left her with tears streaming down her face, Kaya tried to protect her from this pain by standing between the bed and the person with the shot.

Kaya got even more protective when Susan started chemotherapy. Sniffing her head to toe when she returned home following the first infusion, Susan believes she could smell the chemicals in her system. "During the days and weeks that I was recovering from chemo, Kaya literally would not leave my side," she says. "My mom and friends would have to coax her

off my bed in order to eat or go outside. She would lie quietly with me for hours and hours when I was not feeling well. If I slept, she slept. If I lay awake, she would peer into my eyes with a concerned care.”

Once when Susan was really sick, and another time before she was hospitalized with a serious fever, Kaya woke Susan’s mom up in the middle of the night to check on the patient. Both times, Susan was sleeping soundly, but within 30 minutes began experiencing symptoms. Both Susan and her mom feel that Kaya sensed something was wrong and was trying to help. Though Kaya has since passed away, Susan is grateful that she was with her throughout her cancer treatment, and she continues to foster other Great Danes.

Your Circle Is Wider Than You Think

What should young people do with their lives today?

Many things, obviously.

But the most daring thing is to create stable communities in which the terrible disease of loneliness can be cured.

—KURT VONNEGUT

You are part of a community. Several actually. We all are. There are those with whom we talk about books or movies, those we go hiking or biking with, those with whom we love to just hang out, those we love to eat out or cook with, those we know from a particular place such as church or school, those we see regularly, and those we only connect with virtually or talk with on the phone occasionally.

Try This

Take Stock of All the People in Your Life

Take out a journal, notebook, or even a poster-board and begin to make a list or mind map of the communities you belong to. Your family is one. Your friends, another. You can create communities by era (high school, college, etc.) or areas of your life (work, school, hobbies, those who live near you, those who live far away, those you have lost touch with, those you see every day, those you miss) or whatever system that works for you. Include acquaintances, coworkers, role models, anyone who you know personally; they should all go on the list, even if you haven’t connected with or seen them in a long time.

I am always amazed at how huge my list is, and it's never actually exhaustive. Some of my communities include: high school, college, sorority, camp, work, professional, graduate school, church, cancer, outdoor enthusiasts, writers, friends of friends, book club, family, river guides, and various pen pals through the years. Many people appear on several different lists and I keep adding to it as I make new connections and I remember people I haven't thought of in years.

Why is it useful to write down the people you know and the various communities they fall into? Because you don't really realize how many people are indeed in your life. You are surrounded by people who love you. Seeing it in black and white (or better yet, full color) will make it more real for you, and give you a resource to turn to when you are feeling alone.

What does community mean to you?

How has community impacted your life up to this point?

Try This

Connect with Three to Five People Each Day or Week

It's OK to text, e-mail, or Facebook message but use a variety of methods to connect, including phone calls and face to face.

How many different people can you connect with this week?
This month?

Keep a running tally and have some fun with it! Don't have an agenda for your connections, just reach out. If something occurs to you to ask for, then do so. If help is offered, take it.

The Cancer Community

I refuse to join any club that would have me as a member.

—GROUCHO MARX

*Communication leads to community, that is,
to understanding, intimacy and mutual valuing.*

—ROLLO MAY

Like it or not, once you have been diagnosed with cancer, you become part of a club. It's not as exclusive as it used to be, unfortunately, but it can

become a community if you choose. You listed the communities you belong to, and after you have been dealing with cancer for a while, fellow survivors you come into contact with can make up a new category as well. Whether you meet them at a retreat, in a support group, or at the doctor's office, these fellow travelers can become an important part of your tribe. They get it. They have been there, and they are typically up on the latest cancer news. Thinking about a holistic approach? Your cancer buds probably know something about that. Looking to get into a clinical trial, ask a fellow survivor. Looking for a second opinion or a good book on a cancer-related topic, they can point you in the right direction.

All the personal stories I'm sharing in this book came from my cancer posse in some way. Either I knew them personally, or they were connected to me through someone I had met along the way. Jonny Imerman of Imerman Angels connected me to a number of single survivors. Some research conducted by the LIVESTRONG Young Adult Alliance (now called Critical Mass) a few years ago showed that Jonny was the best connected in that community, and anyone who has ever met him is not surprised to hear that. In his signature black Imerman Angels t-shirt and jeans with his shiny bald head, Jonny is easy to spot in a crowd, but it is his exuberant personality that he is really known for.

I first met Jonny in 2008 at the LIVESTRONG Summit in Columbus, Ohio. He came in for a hug and flashed me his megawatt smile. Talking with Jonny gives you the feeling you're the only person on the planet as he stands close, never breaks eye-contact, and often maintains physical connection throughout the conversation. Jonny never forgets a name, and typically remembers the diagnosis as well. For years he would tell me I was still the only granulosa cell ovarian cancer survivor in the Imerman Angels database.

Jonny has been such a force in my survivorship, advising me early on about health insurance issues, and taking time out of his busy schedule to talk on the phone or have dinner when I'm in Chicago. He has been instrumental in the lives of so many others as well. His organization pairs cancer "fighters," those newly diagnosed, with cancer survivors like me who have been through the process of treatment and recovery. This mentorship provides an amazing opportunity to talk with someone who has been there and done that, and can share information and hope. Jonny truly believes these mentors are like angels to the freshly diagnosed when they are in the midst of so much fear and turmoil.

The idea for the organization grew out of his own experience of talking with other cancer patients in the hospital. "My room was always filled with family members and close friends," he said, "but in many other rooms, I saw people fighting cancer alone, lying in bed motionless, watching television or staring into space." He said he felt guilty at his abundance of support and

positive energy, and vowed that if he was given a life after cancer, he would use it to help others.

I also experienced the power of the cancer community through First Descents, a nonprofit that brings together young adult cancer survivors for a week of adventure in some of the most beautiful settings in the world. One of my fellow campers said it best: “This is a cancer camp that’s not about cancer.” While we all knew we shared a cancer background and talked about it informally throughout our time together, it was never the focus. Enjoying each other, the great outdoors, and the challenge of a great adventure were the cornerstones of this experience.

The most beautiful gift of this program for many is simply being taken away from the grind of daily life to experience equal measures of tranquility, friendship and adventure in a stunning natural setting. As our staff on the Montana kayaking adventure reminded us before our graduation paddle, we have only right here and right now. When you are paddling a class III rapid called Bone Crusher or trying to avoid Can Opener Rock, cancer is the furthest thing from your mind. I am so grateful to have had this experience, and that nonprofits like First Descents exist to challenge and support us through this journey.

These are just two examples of the programs, resources, and support systems where everyone can find community in the cancer world. There

There are a number of incredible resources for cancer survivors, from those offering Reiki and massage, retreats and camps, financial support, or granting of wishes to the terminally ill, and just about everything in-between. If you have a need, the organization or program to fulfill it likely exists. Whether you are looking for a support group, a cancer mentor, a way to raise money and support a cause you care about, or coaching, a quick Internet search should yield a variety of resources. There is a long list at the end of this book, but new ones are popping up daily. Most of the organizations and programs will provide links to other services as well, so look for resources on every website. Many programs are national or global in scope, while others exist in your local community or through your hospital or doctor’s office. Ask what is available, and speak to a social worker about options for you.

are programs for young adults (more and more all the time), teens, families, groups differentiated by gender, specific cancer types, and geography. There are active outdoor opportunities, quiet meditative retreats, strictly educational conferences and programs, and everything in-between. Check out the resources section for some ideas and search the Internet for a variety of other opportunities that meet your specific needs.

Whether you listen to the Stupid Cancer radio show for young adults, attend a retreat put on by Camp Mak-A-Dream, or learn to surf with Athletes for Cancer, I encourage you to find a way to get involved with your new community. It will help to connect with others who understand, and will definitely help you feel less alone.

Brian, a 32-year-old stage IV, non-Hodgkins lymphoma survivor, used several services for cancer survivors from First Descents to Imerman Angels and Gilda's Club. He attended Stupid Cancer's OMG Conference and found it as well as their website and radio show extremely helpful. He also felt fortunate that a counselor he saw as a child reached out to him when he was diagnosed and offered to treat him for free; in addition, he and his younger brother, who is also a survivor, joined a support group for young adults that has been immensely helpful as well.

Heather Hall is an osteosarcoma survivor who works for Gilda's Club. She attended a session at Camp Mak-A-Dream a few years after her diagnosis. "Going there really made me realize there were others like me," she said. "The biggest thing is that you're NOT alone. There are so many resources. It is great to connect with others who are dealing with this."

What role would you like your new cancer community to play in your recovery?

What types of programs appeal to you? Active, outdoors, informational conferences, or small group retreats?

Imerman Angels is a one-to-one mentoring program matching newly diagnosed cancer patients or caregivers—"cancer fighters"—with those who have been through the same type of situation—"cancer survivors." People are matched with others who are similar to them on a variety of points—diagnosis, gender, age, geographic location, even religion, if that is noted as important.

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Gilda's Club, founded in honor of comedian Gilda Radner, who died of ovarian cancer in 1989, offers social and emotional support for cancer survivors and their families at a variety of clubhouses in cities across the United States.

Stupid Cancer is a nonprofit organization that empowers young adults affected by cancer through innovative and award-winning programs and services. They are the nation's largest support community for this underserved population and serve as a bullhorn for the young adult cancer movement.

Camp Mak-A-Dream provides medically supervised, cost-free Montana experiences, in an intimate community setting, for children, young adults, and families affected by cancer. Find more information about these resources and a variety of others in the back of the book.

Help Is Out There—If You Ask

Asking is the beginning of receiving. Make sure you don't go to the ocean with a teaspoon. At least take a bucket so the kids won't laugh at you.

—JIM ROHN

I think that the most difficult thing is allowing yourself to be loved, so receiving the love and feeling like you deserve it is a pretty big struggle. I suppose that's what I've learnt recently, to allow myself to be loved.

—NICOLE KIDMAN

Learning how to ask for help is one of the most valuable lessons I've learned from my cancer diagnosis. I was never good at asking for help, preferring to be a fiercely independent and self-sufficient person. Asking felt uncomfortable to me. It felt like a weaker position. What if the person I ask says "no?"

When I received a new TV for Christmas one year and faced the task of getting it into my house after driving with it for eight hours, I chose to carry it by inches rather than ask someone to help. When I broke my ankle, I was insistent upon being my typical independent, strong, and capable

self, so I rarely let anyone see how hard that time was for me. I expected people to intuitively know I needed them, and what I needed, and come rushing over to provide it, and when they didn't, I was bitter. I spent a lot of time feeling sorry for myself, and complaining, but a very poor job of explaining to people what I was going through. Had I been willing to admit that I was feeling down and lonely and helpless, I have no doubt my friends and family would have shown up for me in incredible ways to help me through it.

My friend Jenifer Madson's book *Living the Promises*, states: "We are never at a loss for support; only the words sometimes to ask for it." I was always surrounded by love and support, but I didn't know how to ask for what I needed or how to receive it when it was offered until I got cancer.

Try This

Get the Support You Need

1. Take stock of all the people in your life. (You did this already with your communities.)
 2. Figure out what you need.
 3. Ask for help.
 4. Keep people in the loop and be open about your challenges.
 5. Receive graciously and gratefully.
-

When I got cancer, things were different. In many ways, having cancer was much easier than having a broken ankle. Even though I didn't feel well from the treatments much of the time, I still had full use of my body and people immediately wanted to know what they could do to help. My initial answer was, "I don't know." It was so new, and I didn't yet fully understand what impact this disease would have on my life.

I did know from experience that if I wanted help, I'd better figure out what it was that I needed and tell people. I decided to be completely transparent this time around, and really share what I was going through both physically and emotionally. I began posting regularly on a health website about the latest test results, treatment protocols, and emotional hurdles I was dealing with. I probably shared way more than I needed to, but it was cathartic for me.

Try This*Keep Friends and Family Updated On Your Condition and Needs*

Use a service like Carepages, Caring Bridge, or Facebook. My favorite is **MyLifeLine.Org**. This nonprofit site allows patients to share not just in a journal format and upload photos, but also has a treatment calendar, inspirational quotes, medical information, and a donation function to support the patient. It is just for cancer, and allows users to keep information private (to only those you invite or allow) or public to connect with other patients and survivors.

A service like this significantly cuts down on the number of times you have to repeat information, and makes it easy for loved ones to get updates. Keeping health and medical information separate from social media might be preferable to some. You have to decide what's right for you. My own information on MyLifeLine.org is public, so feel free to check it out if you want by searching on my name.

After I spent some time thinking about what I needed, I sent the following e-mail to a wide audience:

Dear Friends and Family,
 I am always learning to ask for what I need, and getting better at it all the time. Neither my needs nor my problems have changed one iota really during this experience. They are only magnified by it. Everything seems harder (laundry, errands, groceries, work, etc.) or more pronounced (loneliness, fear, and anxiety) or takes longer (writing thank you notes, walking, and returning phone calls). You can help if you are next door or 7,000 miles away. Here's how: Sign up to receive my updates online. Repeating the same story multiple times is just not an option. I don't have the energy. If you see friends or family who should be on the list, and aren't, please share the information with them.

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What I Need:

1. Invite me to do stuff with you—picnics, concerts, movies, parties, meals, walks, happy hour, etc. It is sometimes tough to plan things because I never know how I will feel, so feel free to also just call spur of the moment and say, “Let’s go now.” Keep asking me even if I am not feeling up to it the first time.
2. Call to check on me periodically or drop an e-mail to just let me know you are thinking of me. I love getting cards, but don’t want flowers or gifts unless it’s something I specifically asked for or a book or movie. There is no room in my tiny condo. If you really want to buy me something, here are some things I could use: -New hammock chair for my deck. My old one disintegrated and I miss relaxing out there with a book. -A juicer. Every book I read talks about the benefits of juicing, and I have many veggies from the garden I could use. -Airline miles or ticket vouchers. (Thanks Darryl & Kay for your generosity of this front already.) -itunes gift cards (Abby sent me one this week and I realized this is perfect. Because I don’t have a TV, I buy episodes online and music too.)
3. Bring me dinner or take me out for brunch or ice cream or coffee!
4. Easy stuff for me to make or eat are helpful because often nothing sounds good and I don’t have the energy to cook. Cut up fruit, instant oatmeal packets, yogurt, soup, or other stuff I can freeze (in individual servings is even better), small servings of salads (quinoa, tuna, broccoli, or other healthy stuff), and single serving beverages.
5. Offer your expertise deciphering medical bills or insurance paperwork.
6. Invite me to scrapbook with you (I am so behind).
7. Call and ask, “Do you need anything this week, today, right now?”
8. Send me funny stuff (laughter helps a lot) by mail, e-mail, carrier pigeon.

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9. Ask me to take a walk (I am slower these days). It is so hard to get motivated to exercise, but I need to walk since I can't do much other stuff.
10. Loan/Give me a good book/movie/CD.
11. Offer your volunteer time, expertise, retreat location, or just a donation to support the work I'm doing for singles with cancer. This is important to me as I realize how hard this is without a built in support system.
12. Pay for a Reiki session, a massage, or a cleaning service.
13. Invite me on a road-trip, to stay with you for a few days, or spend the weekend at your cabin. I have been staring at my own four walls for a while now.
14. Give me a hug (even a virtual one is not bad). Hold it longer than usual.
15. Drop by with a DVD and some Cherry Garcia.
16. Help me figure out a good, relaxing three- to five-day get-away for the end of treatment so I have something to look forward to. Cancer is expensive, so it should be somewhat easy on the budget too.
17. Tell me you love me (or like me a lot). So many have already done this—Thanks so much!
18. Offer to go with me to chemo or Dr. appointments.
19. Just offer to hang out—it gets lonely not being able to plan fun stuff as usual.
20. Offer to unload my dishwasher, mop my floor, vacuum, wipe down my microwave, or do a quick tub cleansing. This can even be on the way out to a movie!
21. Keep being the great friend, parent, sister, aunt, cousin, co-worker you have always been, and don't be afraid to ask me anything or tell me you don't know what to say. Just saying something is enough. Thanks for being here for me, and for asking what you can do. I hope this helps.

—Tracy Maxwell

Download this letter as a Word doc that you can edit for yourself at IAmTracyMaxwell.com.

The response I got to this request was overwhelmingly positive. Almost all of the items on the list were fulfilled by friends from far and near. People flew to Denver to be with me for EVERY chemo session, staying for several days afterward to take care of me when I was feeling my worst. I received hundreds of cards from friends and even friends of friends. Hats, scarves, wigs, and any number of fun and funny gifts also made their way to my door including journals, frozen food, movies, gift cards, and lots and lots of books.

Most interesting was the positive response I got to the e-mail itself. People were relieved to have some guidance about what they could do, and so anxious to be able to help in some way. The two biggest responses I got from months of treatment were to my e-mail asking for specific help and my post telling people not to worry about saying the wrong thing. I told them anything they said was better than saying nothing, even if it was simply, “I don’t know what to say,” or “I’m sorry you’re going through this.”

It is easy to sit at home feeling sorry for yourself about everything you’re going through, and lament the fact that people haven’t shown up for you as much as you expected. I definitely had those thoughts from time to time. It is much more powerful to remember that everyone is busy going about their own lives. They have no idea what you are going through. You have to actually share, and ASK for what you need. Taking some time to really think about what would be helpful to you and asking for it will pay huge dividends. It is not always easy to know, and your needs will even change over time, but don’t overlook this important step in the process. If someone said to you, “I need a hug,” would you think he or she was weak? I doubt you would. You would just offer a hug.

Two years ago, I heard about a surf camp for cancer survivors in Maui, and I really wanted to go. Even though the camp, operated by Athletes for Cancer, is free, I couldn’t afford the plane ticket. I might never have gone had a friend not suggested that I ask for help in getting myself there. Another friend flies constantly for work, and has more than a million frequent flyer miles. I had asked her before to help support travel scholarships for single survivors to come to my events, but never for help for myself. She happily agreed to secure my ticket with her miles.

People want to contribute to us, and by not asking, we deny them that opportunity. What do you really need right now? Find a way to ask for it and then receive it gratefully.

Are you comfortable asking for help?

If not, what could you do to change that?

Are you a good receiver? How do you know? Examples?

Learning to Receive

*Be thankful for the least gift,
so shalt thou be meant to receive greater.*

—THOMAS A KEMPIS

What if you gave someone a gift, and they neglected to thank you for it—would you be likely to give them another? Life is the same way. In order to attract more of the blessings that life has to offer, you must truly appreciate what you already have.

—RALPH MARSTON

For some of us, receiving is difficult. It's something I haven't done well in the past. From compliments, to help, to money, I tended to deflect more than accept. But in order to give, someone also has to receive. This is a cycle that speeds up the more we practice it. Give without receiving and you deny others the opportunity to contribute to you, which in turn makes it more difficult for them to receive from others.

Try This

Some Things to Practice in Order to Learn to Receive

1. Keep a receiving journal to record all the things you receive each day. (Bonus points for things you actually ask for. Even if others don't always say yes, asking is so powerful. Keep doing it.)
2. Practice gratitude for all that you have. (I posted "gratitudes" as my Facebook status for several weeks to do this publicly.) Keeping a gratitude journal is great as well. Write down what you are grateful for everyday—at least five things, but as many as you can. Pay attention to repeats. It is OK to be grateful for the same things repeatedly, but be conscious about looking for new things all the time. Be open to the abundance in your life! (Sara Ban Breathnach first popularized the gratitude journal in her book *Simple Abundance*.)
3. Mike Dooley of TUT.com suggests: Visualizing what you desire in your life without worrying about "how" you might receive it—knowing that thoughts become things.
4. Consciously ask for help at least twice a day whenever possible.

5. Break patterns, doing things that you haven't done or said before—this brings new energy and connections.
 6. Check out The Receiving Project and sign up for the free 32-day e-course on the Law of Attraction.
-

Paying It Forward

Alice, a 31-year-old breast cancer survivor, talked about how much she received from others, including financial support from her parents and even from her church. In addition to a large cash gift to help her pay her property taxes, church members also donated household items she could sell at garage sales. “I could never pay it all back,” she said, “so instead I pay it forward.”

That is one of my purposes in writing this book: to pay forward all the great advice, share the resources, and offer the hope and inspiration to others that so many have given me. I got a great lesson in paying it forward a month after finishing chemo. I decided at the last minute to fly home to surprise my family for Thanksgiving. I made the decision after finding out they would be hosting a 90th birthday party for my grandfather who had been diagnosed with pancreatic cancer and given two to six months to live 16 years earlier. I didn't want to miss that!

In my rush to work out all the details of this trip, including borrowing a car at the other end so I could get from the airport to my parents' house two hours away, I left the house without my wallet. At first, I didn't think I would even be able to get on a plane without an ID, but it turns out, you can. You just have to go through every single security screening, including being patted down and having your luggage hand searched.

That hurdle cleared, I began thinking about the fact that I had no money or credit cards and a layover on a holiday. Yikes. What if something happened with my flights and I got stuck somewhere? I quickly called a friend and asked him to wire me \$80. While I was waiting for the money to come through, I heard an announcement that my flight was delayed. Yikes again. If I missed my connection, I would for sure miss Thanksgiving dinner with my family and stood a better chance of getting stranded somewhere. I headed to my gate and explained to the agent what was happening with me. Was there a direct flight I could get on instead? Turns out, yes, but I would have to hurry. I wasn't sure my cash would be there yet, and shared my concern. She handed me my new ticket and told me to run.

When I turned around, the woman behind me in line, who had overheard my entire story, was holding a \$20 bill toward me. Tears sprang to

my eyes as I asked for her address to return the money. She told me to pay it forward instead. I got home that day with \$100 in cash (my \$80 came through too) and spent a fantastic holiday with my family.

Five years later, I also had the opportunity to pay it forward. I had landed in Denver, home from a conference, and was waiting for delayed luggage and a friend who was picking me up. Sitting in the baggage claim area, I overheard a woman talking on the phone. When she hung up, she turned to me and said, “I left my wallet on the plane. How stupid is that?” She was clearly flustered, and started explaining what that would mean for her day. I gathered that her husband was coming to get her from Aspen, but that it would be several hours. She told me they did find her wallet, so she would get it back, but she didn’t have any money right now.

I offered her some fruit I had in my purse, and then it occurred to me that this was my opportunity to pay it forward. I told her I was going to find an ATM to get her some money and she said, “If you could just buy me a bottle of water, that would be great. I’ll be fine as long as I can take my medicine.” She had recently had a root canal and was on prescription pain killers.

When I came back and handed her a \$20 bill, she said, “Oh no, I can’t take that. Five dollars would be more than enough.” When I asked how she planned to eat while she was waiting several hours for her husband, she reluctantly agreed to take the money, but I could tell it was very hard for her to do so. She remarked, “It’s so easy to give, and so hard to receive.” I shared my own efforts to become a better receiver and my story of someone helping me similarly almost exactly five years earlier.

With tears in her eyes, she thanked me over and over again, and by then, I had teared up as well. She had mentioned paying me back several times, and I flatly told her I wouldn’t take any money from her, but that she could definitely pay it forward as I had. I told her, “You have given me a great opportunity to pay forward a five-year old favor, and I appreciate your allowing me to do so.” She got up and gave me a hug, sat down, and then got up to hug me again.

Have you had opportunities to pay it forward in your life?

What is the nicest thing ever done for you by a stranger?

What things have you allowed yourself to ask for help with? What else could you ask for?

Every Friend Matters

Friendship marks a life even more deeply than love.

—ELIE WIESEL

True friendship is like sound health; the value of it is seldom known until it be lost.

—CHARLES CALEB COLTON

Your job won't take care of you when you're sick.

Your friends will. Keep in touch.

—ANONYMOUS

I am lucky to have many good friends who contribute to my life in a variety of different ways. I see some more than others, and though a few drift away, I am constantly making new connections. Each friendship is valuable to me.

Like any relationship, friendships take effort to build and maintain. Some are very casual or are based on more superficial connections like shared hobbies or mutual friends. Others are deeper and more meaningful, built with people you feel you can share anything with. Friendships can grow and fade or die. Sometimes the parting is intentional or painful, and other times it's gradual, the slow weakening of a bond that was once important and, then, no longer is.

As the Tracy Lawrence song suggests, when the chips are down, you find out who your friends are. I was lucky enough to have people come out of the woodwork for me when I was diagnosed. Friends of my parents, friends of my friends, and long lost friends that I hadn't heard from in years found some way to show up for me. Some made donations to the Ovarian Cancer Research Fund in my honor, others sent cards, a few brought food, and every once in a while, someone would make a gesture that would bring tears to my eyes for its unexpectedness or kindness.

Like when my friend Heidi surprised me by renting a bright red Mustang convertible to take me to a series of dreaded doctor's appointments and consultations during a particularly difficult time. Her support, and the wind in my hair, cheered me up immensely.

Or, when I returned home after a week away to find my friends had cleaned my entire condo, painted my kitchen, hung curtains and a shelf in my bedroom, built a new bookcase, organized and stocked my pantry, planted wheat grass in decorative pots, bought me a new welcome mat for the front door, and even hung a new piece of art above my fireplace. A pumpkin sat on my kitchen table with a note that read, "We love you and you are NEVER

alone.” It was signed by half a dozen of my friends who had spent their weekend making my home feel cozier. I was so touched and overwhelmed by their generosity and kindness. Their gift is among the nicest things anyone has ever done for me, and it came at exactly the right time.

Or when my friend Judy prepared a picnic dinner in the park featuring a variety of healthy dishes to support my new diet. Knowing she was there to be my advocate and support me has made all the difference in the world.

I already knew I had great friends, but my experience with cancer reminded me of just how great they were, and how very much I was loved. During my most recent recurrence, friends and family donated \$25,000 through a fund-raising campaign to help pay for my alternative treatment that wasn’t covered by health insurance.

I recognize how fortunate I was, and also know that I would not have received a fraction of the help I did if I hadn’t been willing to share what was going on and ask for it. Alli felt the same way when she was diagnosed with stage IV ovarian cancer and given just a few months to live. Though the prognosis wasn’t great, her friends were.

“It was difficult in the beginning,” she said, “because I didn’t really know what I needed, so my friends just assumed, and sometimes the result wasn’t helpful.” When pressed for an example, she shared the day a big group of people showed up to clean her condo right after she’d gotten home from surgery. It was a bit overwhelming, but even worse was that her fridge got completely cleaned out down to condiments being thrown away, and she was in no condition to replace those things.

“At first, I felt guilty about asking for help,” she said. “But there was one incident that provided a turning point. I ran out of toilet paper. Someone was coming to bring food that night, and I called to see if she could pick up TP on the way. She was so relieved to have a request, and that was when I realized how important it was to share what I needed.”

After that, it was easier to let people help with laundry, groceries, and prescriptions. Those little things made a huge difference, she said, and led to bigger things. People from her church provided meals twice a week for a year and one friend even went clothes shopping for her. “She would go to the mall for me and bring me options to choose from because I was just too weak to walk around that much.”

“I was really lucky,” Alli said. “When I was extremely sick, and thought I was dying soon, friends made a schedule to be at my house almost everyday. They didn’t want me to be alone. Another group of people got together and decided I needed distraction and entertainment. We had girls’

night regularly that involved movie outings or rentals and they even brought snacks so I didn't have to do anything. That really helped my spirits."

Friends drove her to appointments when she began having seizures and couldn't maintain a driver's license, helped her with flights to participate in camps and programs across the country, helped clean her house, or paid for a service.

Alice said her neighbor fed her dinner every day for a year. "It was a huge deal," she said. "It was often the only human interaction I would have all day."

Other survivors and caregivers I interviewed mentioned how painful it was when friends fell away during cancer treatment.

Aileen said, "I lost so many friends during cancer. Not only did some people not show up for me, they didn't even return my calls." Her boyfriend stuck with her through treatment, but the experience took too much of a toll on their relationship, and two months after she finished treatment they split up. She understands how difficult it was for him. "Co-survivors are going through a lot too," she said, noting that he had already been through this before when his ex-wife's mom died of breast cancer. She said she's still afraid to connect with people because she worries if she gets sick again, they will leave her. But she's trying to look more at what is there rather than focusing on what isn't. "We have to appreciate what we have," she said.

Lila witnessed something similar when she served as caregiver to her friend who died of ovarian cancer. Jo Ellen was in her 50s when she was diagnosed, and she and Lila had been friends for 15 years, mostly as travel buddies. "The most painful thing for me was to know that there were people who disappeared from her life," she said. "It was difficult and surprising to her as well. She got it from a cognitive perspective, but it didn't make it easier for her to deal with." Lila said she was the only one her friend could talk to about things, and emphasized that as a friend, family member, or caregiver, it's important to be upfront about what you can and can't do.

"She had a closer friend who helped with physical care-taking. I was clear that I could lend emotional support, and that she could call me anytime day or night," Lila said. "At some point, I would always ask her, 'How is your soul?' That was my role with her."

The people who come through for you might not be the ones you expect. Lesley, a 36-year-old breast cancer survivor, said, "One of the biggest things I learned was that it's often the people you least expect who show up, and the people you think will be there who disappear when things get rough."

Don't spend a lot of time worrying about who is helping or who is MIA. Just be thankful that someone is there. I felt the same as Lesley, and was often amazed that the people closest to me were not necessarily the ones to help out the most in a crisis, and it is sometimes surprising who does show up when I least expect it. I have learned that things rarely unfold the way I think they will, and not to get bent out of shape that so-and-so has been absent.

I really don't take it personally because we all have busy lives, and can't always show up the way we would like to all the time. It doesn't mean anything about me at all, and reading into it that someone doesn't care is unfair to them and painful to me. Perhaps it is more difficult for those closest to us to handle what we are going through, making them more likely to check out. Like Aileen, I would rather focus on who does show up and be grateful for that.

I still struggle with which friends fall into the category of those you can ask to drive you to the airport, or list as an emergency contact, and I think a great deal about the relationships in my life and the place they hold. I try not to get too bothered anymore when friendships fade. People grow apart for valid reasons: our interests, schedules, or responsibilities change. Or we find that we have different needs and seek out new friends to better meet them. I do my best to appreciate the friends that are part of my life at any given moment. There are many. You know who you are.

Who are the friends in your life you can count on when the chips are down?

Which friends have you helped and supported?

With whom would you like to cultivate a closer friendship?

