# I Wish I Had Known

## Gratitude

With deepest gratitude, I thank

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## 1-I Wish I Had Known

When I was a child, the adult world seemed simple. Looking at my parents and neighbors from a suburban child’s eye, there seemed to be predictability to adult life. Some adults went to work, some stayed home, mothers drove carpools, and fathers threw baseballs and fixed cars. The adult world just seemed to march on without missing a beat.

As I moved through adolescence, my perspective widened. Mr. McCashen, one of the dads in the neighborhood, traveled for business. While on business, attackers stole his wallet. They beat him so badly he was left with severe brain damage, limited speech, and inability to use his left arm, as well as other impairments. I’d watch him limp to the mailbox with the gait of a toddler. He never got better. He couldn’t work, speak, or comprehend what he read. His life was taken. His family’s life was forever altered.

Then there were the Koltens, who had six children. They always played together outside in front of their house. Passing by their house, I could see their mother watching over her brood through open curtains. Then one day, the curtains were closed. One day turned into ten, and then a few months passed. It was then I overheard whisperings about the youngest Kolten. He had slid down in the highchair, got caught on the belt strap, and died. After that, I never saw them again. Maybe it was the making of my yet-to-be career as a psychologist, but I wanted to know how they were feeling and coping. What went on behind those closed curtains?

Years passed and I fulfilled my career dream to become a psychologist. People walked into my office to share depression, anxiety, loss, conflicts, and more. They revealed emotions and thoughts they often kept from loved ones and friends. I learned from their bravery and experiences. Yet, in the beginning of 2016, I was on the precipice of a crash course that only firsthand experience can teach. I was diagnosed with multiple myeloma, a blood cancer, tipped off by a fractured vertebra in my back.

Armed with notebooks of information about medical procedures and medication, I felt ready for what would ensue—only to find out there were missing chapters. How do I tell my loved ones what is happening? Why do I start weeping even when I don’t feel sad? Where did this overwhelming anxiety come from? What should I tell my colleagues? Will I die? There is so much I wish I had known.

And, so it is, that I set out to write this to blend my professional knowledge with experiences to help people navigate these times. After all, we all just wish we had known.

## 2-Getting the News

We learn our loved one has suffered a serious injury. We receive a cancer diagnosis. Our spouse has had a heart attack. We carry our child into the emergency room with unexplained symptoms. A loved one sinks into a deep depression and is unable to function. These moments mark our lives; our worlds become different from the days before “it” happened.

Medical crises throw us into unfamiliar territory. Physicians and other medical personnel offer opinions and lay out potential treatments, but there is little to no discussion about how this will affect our families, emotions, or overall functioning. The medical team's focus is on getting us well. Questions fill our minds as the next steps are laid out. Some questions are asked, but others are not because decisions need to be made. Appointments end, and we are left on our own to sort through our reactions, often wondering if what we are feeling is normal.

Specific reactions depend on each individual and situation, but we also know that the brain kicks into high gear to manage a crisis, creating certain reactions.

Whether the crisis is just happening, you are well into the process, or you have come through the other side, understanding the inner workings of the brain, emotions, and behavior can help you manage — and hopefully heal — from the trauma of a medical crisis.

## First Reactions

### Cindy's Journey *I Want to Get Off*

I sit across from my doctor as he explains the diagnosis and draws pictures illustrating how cancer cells differ from other blood cells. I nod and ask questions, but inside, emotions pound against my heart. Anxiety, uncertainty, and sadness swirl as my outside demeanor takes on a falsely calm image. Little do I know that this is just the beginning of an emotional rollercoaster ride I can't get off.

We've all experienced moments that leave us shaking, suddenly aware of how our lives can change in a moment. Driving down the road on a sunny day listening to a podcast, a car swerves into your lane, only to miss your car by inches. As you lay on the horn and swerve your car out of danger, adrenaline pumps through you. Your heart races, hands tingle, and you have overpowering thoughts about the near miss. "Phew! That was close!" As you continue to drive down the road, adrenaline and symptoms subside as your brain lets you know you are safe again. However, when you tell the story to another, you feel a resurgence of reactions. You re-experience the shock reaction, because your brain has linked the emotional and physical responses in your memory. Even though you are safe when talking about your near-miss experience, the brain's connection to the event causes you to re-experience some of the sensations you felt as you swerved out of the way of danger — just to a lesser degree. Over time, the brain replaces the memory with calmer responses.

Unlike the near miss in the car, the psychological shock of experiencing a significant medical event doesn't end when we drive away. The ongoing nature of illness, accidents, and the unknown that come from a diagnosis create a cascade of feelings and reactions. When experiencing a health crisis, we often don't have prior experience to help us know what to do. We don't know how to do "sick or injured." We are faced with issues that demand our attention, appointments to be kept, and decisions to make as we redefine what we think of as our "real lives."

*When presenting a diagnosis, my primary focus is to present the information in a clear manner. Specifically, what needs to be done (now, short term, long term) and not trying to bite off too much at a single visit. –Dr. Ted Lee, Hematologist and Oncologist*

Swirling emotions are unsettling because they are a reminder of what is happening, and that life has changed. While there are specific emotions that are typical, there is no wrong way to experience a medical crisis. Each person has a unique set of reactions based on life experiences, personality, and brain patterns. Let's look at a few of the most common.

## Shock

*Disbelief. Shock. I felt I was branded with a big C on my forehead. –DH*

Shock occurs when our lives take an unexpected turn. Shock propels us into a land of the unknown. It is unfamiliar territory. We aren't sure how we got here, and we don't know where we are going to end up.

*I was in shock from the accident that left me feeling oddly calm and dazed, but I remember I wanted the next steps to start. –CK*

*Shock. This was a cancer I had never heard of. I cried. –NA*

*Devastated. –RF*

*Questions flooded my mind. Will he die? After 58 years, how could I live without him? This isn't fair; he's such a good man. –NL*

Shock quickly moves into other reactions because the body can't sustain high adrenaline for long. While the initial shock can be short-lived, it can loop around and hit us again when another unexpected turn occurs along the journey.

*I often think of myself in this journey as the luckiest/most unlucky person. I decided to have elective surgery to have my sigmoid colon resectioned. During that surgery, the doctor saw what he thought was cancer. He did a blood test that confirmed his suspicion, and he aborted that surgery. When I was awakened from surgery and told the operation was aborted, I was shocked. My thinking quickly moved to, "Okay, let's get this taken care of." A hysterectomy, chemo and two more cancer diagnosis later, I am still shocked that it all has happened. –MT*

## Anxiety

*When told I had a brain tumor, I was overcome with total fear. –JZ*

Anxiety is a natural reaction to a threat. Having a chronic illness or chronically ill loved one is a threat to the status quo. When people receive a diagnosis, it is logical that some level of anxiety will be experienced.

Anxiety can be experienced through physical symptoms, such as nausea, difficulty sleeping, trembling, and tearfulness. Others experience anxious thinking, such as worry, intrusive thoughts, and phobias.

> *I was in a mental panic. There is no known cause or cure and seeing two pages of Google results was extremely disheartening. It was emotionally consuming and numbing all at the same time. I felt hopeless and confused that this seemingly improbable thing was affecting our 3-year-old son and our family. –RR*

> *I was scared and terrified. I made sure my affairs were in order. I wrote a letter to my husband, daughter, and sister to open upon my death. –SR*

> *I received a call from the hospital letting me know I had to return to talk about the results of the biopsy of my appendix. Turned out I had a tumor on my appendix and that was why it was inflamed, and I required HIPEC (Hyperthermic Intraperitoneal Chemotherapy) surgery. My initial reaction was disbelief and that there must be a mistake. I even asked if the results had been switched with someone else's. The doctor assured me the appendix and results were mine, I sank into my seat with fear and discontent. I was 25. –CL*

Anxiety feels like our beings are being shaken from the inside out. Trembling hands, trouble focusing, heart palpitations, headaches, and fluctuating emotions pepper our moments. Worry takes over the usual clear thinking of our minds. The variability and intrusiveness of these reactions interfere with our thinking, normal reactions, and view of ourselves.

> *Shock, fear, anxiety and anger. I became a "nervous Nellie" overnight. –JN*

> *Fear struck me because my cousin had died five years earlier from the same disease. –SJ*

> *Getting my diagnosis was like an out-of-body experience. –MB*

> *My father-in-law was diagnosed with aggressive skin cancer. It grew on the top of his head covering his entire head in eight weeks; it was very scary to watch. This was the first time we had to share this kind of news with our kids. It was extremely hard to share and see their reactions. It was hard to see my husband be scared and cry. It has been a tough road. –LH*

For most people, anxiety surfaces through "what ifs."

*Truthfully, I was scared out of my mind. I knew what I had to do, but the fear of not being around for my sons was my #1 emotion. –LL*

*When I got the prostate cancer diagnosis, I felt fear and anxiety wondering how I could tell my loved ones, because my wife's father and mother died from cancer. I was sad and wondered if I would be incontinent and/or have erectile dysfunction. –RZ*

## Anger

*I was furious that I had cancer. I had done everything right (diet, exercise, healthy lifestyle) and it happened to ME! It all seemed so unfair; after all, I had no risk factors. –JN*

Many of us are taught that anger is a negative emotion. However, anger is justifiable when illness, violence, or harm is brought to someone we love or to ourselves. Anger has two sides. It can spark feelings of being powerless or propel us to act. If we act out of anger and do harm, obviously that isn't productive, but sometimes we need anger to spark us into a needed action.

*I am a nurse, and I was angry with myself for not realizing it could be cancer. –KJ*

*My first knee surgery was when I was 16. At 23, I was diagnosed with osteoarthritis. I am a nurse and knew what could lie ahead. I was angry at my body. –LE*

*Anger first. Disgust at the medical community's matter-of-fact attitude because they seemed to forget that for each patient, it is a living hell. –LW*

## Relief

*Initially hearing a list of diagnoses, including Dissociative Disorder and PTSD was a relief. I felt validated and reassured by how the diagnoses described everything I was struggling with. –TZ*

The avenues to diagnosis are often characterized by pain, struggling with daily tasks, feeling unlike our usual selves, and emotions. Going through a protracted period of symptoms often generates a sense of relief once a diagnosis is offered. We think if there is a diagnosis, there is a treatment which can help restore our health.

## I Knew It Was Going to Happen

*My family has a horrible history of dying from various cancers, so honestly, I was not surprised [at receiving the diagnosis]. –LL*

Heart attacks, accidents, serious illnesses, and cancer typically occur with little notice. The suddenness doesn't give us time to prepare and figure out what we need to do. However, for some folks, a diagnosis is the fulfillment of something we've been expecting; we've been waiting for this news. Waiting for the shoe to drop.

> *My mother died of breast cancer when she was 47. At the time of her death, I was 25 and pregnant with my first child and my sister was 7. My husband and I raised my sister along with our children. Because of the occurrence of cancer on both sides of my family,*
> *I always thought "when, not if." –SR*

## It's Just Another Day

> *I didn't look at cancer as a big deal; to me, it was just another life experience. I didn't have an emotional response to my diagnosis. I reacted very pragmatically. Perhaps it is my nursing background; perhaps it is just my personality. –SR*

For some, health diagnoses are taken in stride with minimal upheaval. The event is viewed as another step along the path of life. Treatment and the process are taken with calmness and neutrality.

## 3-Our Brains Lead the Way

Medical crises don't just affect the body. They involve our thoughts, emotions, soul, and brain, but our brain leads the way. Entering a crisis sparks distinct parts of the brain. The first reaction comes from the amygdala. While the name *amygdala* isn't important to remember, it is important to understand that the part of our brain (amygdala) that controls emotions moves to the forefront in the initial stages of a crisis. The amygdala sits up and listens to what is happening around us. Sparked by a threat, the amygdala is prepared to do its job to protect and move us toward survival.

Think of the caveman. He leaves his cave to find food. Spear in hand, he tromps through the wild and hears a rustling. The amygdala moves to alert. Senses become heightened, the heart beats faster, and adrenalin pumps, preparing the caveman to react. Out of the brush comes a mountain lion. Even an experienced caveman is no match for a mountain lion. "Should I fight, run, or stop, all the while hoping the mountain lion doesn't see me?" Thinking through and assessing options are good strategies, but the caveman can't take the time to assess the pros and cons of each option. When in danger or scared, the amygdala is the first responder. It reacts faster than we can think.

If we could slow time down to examine the underlying process, we would see three main ways the amygdala reacts. As noted in How Your Brain and Body

Deal with Treatment post, fight, flight, and flee are common reactions to a medical crisis.

- ***Fight*** One way the amygdala reacts is to fight: take the spear and use it to try to stop the mountain lion.
- ***Flight*** Other times, the amygdala shouts, “Run for your life!” Flight is meant literally, for the caveman’s life is in the balance, and the amygdala decides the caveman must flee to live.
- ***Freeze*** Sometimes, the amygdala urges him to freeze. The body and brain stop; the caveman feels paralyzed.

While we can imagine the probable endings depending on the caveman’s choice, our outcomes aren’t as clear-cut or as predictable when we are faced with a crisis. But our brains go through the same mechanisms as the caveman’s. Whichever path we follow, the brain’s reactions have only one intention: to protect. We’ll look at each of these reactions and how they translate into action at the diagnosis stage of a health event.

## Fight

*Shock quickly turned into action. I immediately started asking hundreds of questions. –MM*

Just as the caveman grabs a spear and prepares to attack the mountain lion, we engage in our battle. We flex our muscles, gather our resources, and yell an internal “Charge!” Off we go to conquer the beast with our 21st-century spear. Our present-day spear takes the form of gathering information, organizing resources, and making decisions.

*I obsessed with the idea that a solution MUST be possible. I spent hours contacting companies, NIH, and physicians to ask about trials that may cross paths with our son’s rare disease. I questioned every decision and the moments leading up to his sudden onset of symptoms trying to pinpoint what could have happened. I longed to try to understand the reasons it happened and how to fix it, believing that if I tried hard enough, there must be a solution. –RR*

*I researched online and networked with everyone I could think of. –SH*

*I developed a love-hate relationship with Dr. Google. I wanted to read as much as I could about my disease, but when I read something I didn't want to know, I cursed Dr. Google. –AA*

*It was as if I was on a mission. I made doctor appointments and began to figure out what I needed to do next and how. –CS*

*After the shock, disbelief, and fear settled down, I moved into warrior mode: coordinate the medical team and get the surgery done ASAP. –RGW*

*I couldn't believe my friend was diagnosed with breast cancer at 45 years old. I quickly accepted it and became a warrior; certain we would fight this together and win. –LF*

*I went into fix-it mode. –KW*

### *Tips for Fight Mode*

When in fight mode, we tend to *focus more on doing than feeling*. Sometimes we don't want to feel, but it is important to be aware of the emotions so they don't build up inside, only to later erupt when you don't want them to.

## Workbook Chapter 3 Our Brains Lead the Way

### *Tips for Fight Mode*

- Make a list of two or three people that you designate as the ones you want to ask you how you are doing. Ask them to use the word *doing* rather than *feeling* to honor your fight mode (at least for now). Be specific about how frequently you want to be asked; you can always increase it or decrease it later. Ask them if they're willing to take on this "job" for you. List these people below.

________________________________________

________________________________________

________________________________________

**Fight** mode places us on high alert and makes it easy to miss important pieces of information. We think we heard it all, but we didn't. In fight mode, as in crisis in general, our memories aren't as dependable as usual.

- Audio record your medical visits.
- Bring someone along with you to important medical appointments as a second pair of ears, or to take notes, so you can just listen.

It is important to be careful with whom we spend time.

- Stay away from people who ask prying questions. People who pry create a feeling of rage and generate a feeling as if they are using your crisis for gossip.
- Avoid know-it-alls. When we are in fight mode, we don't want to hear dissenting opinions, because it distracts us from our well-thought-out plan.

Keeping a routine is important in fight mode, because when following routines the brain doesn't have to think and make decisions about ordinary tasks. Maintaining routines preserves energy for creating plans and gathering needed information.

- Look for two or three routines from your daily life you can deliberately keep during the challenging period of diagnosis.

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**Fight** mode takes energy. It's important to occasionally distract yourself and let your system settle so you're not further taxing your health.

- Create a list of five mind-distracting activities that fit your specific health situation. Ideas include work/volunteer, if possible; exercise; social interaction (sports, games); crossword or jigsaw puzzles; gardening; playing with children; cooking; repetitive prayer; or singing.

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## Flight

*Much of the time, I was in denial of the nature of my 41-year-old daughter's cancer. I just couldn't face it. –JG*

For the caveman, flight is literally running away from the mountain lion in an effort to save his life. As the mountain lion gets closer and closer, adrenaline propels him to run faster to try to escape. When we or someone we love encounters a medical crisis, we feel the imaginary jaws clamp down on our necks, squeezing the life that we once knew out of us. Running away through denial, refusing treatment, overfocusing on tasks in life, or seeking momentary escape allows us to feel some control over a situation that causes us to feel out of control.

*It's official. I am overwhelmed and freaked out. The enormity of what lies ahead and what is going on in my body has hit me. I want to run away. –CS*

### Tips for Flight Mode

When in flight mode, we tend to be *overwhelmed by emotions* that make us want to escape. Thinking about the details and gathering information can increase our distress, so it is important to enlist others to help with these tasks.

If your response is primarily flight, consider building a team around you to support your need to escape yet help you keep track of valuable information.

## Workbook Chapter 3 Our Brains Lead the Way

### *Tips for Flight Mode*

- Make a list of two or three friends/family that you would like to have on your support team. Choosing someone with a medical background is helpful, but not crucial. Meet with them to talk about what you want them to do.

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- As a group, decide who will go to which medical appointments. Record them on a shared calendar (Google calendar, Outlook.com, etc.) You can also share this calendar with others if you choose, such as family, to keep them up-to-date.
- Audio record your medical visits so all team members can hear what has been said and stay up-to-date.
- Have the person who accompanies you to medical appointments take notes, particularly the main facts you need to know, so you can refer to them when you feel ready. After a medical appointment, the team member is to ask if now is a good time to tell you three pieces of information. If you hear one piece and that's all you can handle, tell them that's all you can listen to right now. It helps to add that you are feeling overwhelmed because that gives the helper clarity as to why they need to stop. The helpers need to know these "rules".

When in flight mode, grounding activities are good. Grounding activities are those that keep us more present in the here and now — hence, less likely to take flight. Ways to be more grounded when in this mode include engaging one or more of the senses (taste, touch, smell, sight, sound).

## Workbook Chapter 3 Our Brains Lead the Way

### *Activities*

- Listen to music
- Eat enjoyable foods
- Drink warm/cold beverages
- Smell scents that bring positive memories. Put a whole citrus fruit in the freezer and when frozen, take it out and smell it. The aroma of the citrus can be grounding. Some people use aromatherapy diffusers.
- Be in nature, which is full of sights, smells, sounds, and touch
- Spend time with pets
- Lie under a weighted blanket
- Wear clothes that are comfortable and have a texture you like

Some actions are particularly *un*helpful to take when in flight mode.

- Don't listen to the medical visit recordings unless you have moved into fight mode, because hearing the information in medical jargon can increase anxiety.
- Don't visit Dr. Google.

## Freeze

*I didn't really hear what I was being told. –LVB*

Freezing manifests as a surreal experience. The caveman tries to shrink his body behind the bush so as not to be seen by the mountain lion, even though he knows his human scent will be detected by the beast. There is no hiding, but when in freeze mode, we try. In freeze mode, it is hard to believe what is happening. Life around us feels unreal. It feels like time is suspended.

> *I feel like I move from one room to another, never walking down the hall. Just boom, I am in this other space. A space that is unfamiliar. The walls are fluid, not creating a defined space. I could run into a wall, and it would push further out, only to bounce me back into this amorphous space. There is no furniture, the walls are swirled with pale colors, and the ceiling is beyond my vision. –CS*

> *I found myself a doddering, weak, shuffling soul and was shocked. I felt as though I would collapse from within. Not fall over — just crumble within. –BK*

### Tips for Freeze Mode

When in freeze mode, much of the world around and inside of us feels overwhelmed. We want time to stop. We don't want a lot of input. We want peace. We want stillness. We want calmness. Unfortunately, in a medical crisis, these desires are difficult to attain.

## Workbook Chapter 3 Our Brains Lead the Way

### *Tips for Freeze Mode*

Although freeze and flight modes are different from one another, they have similar features that prompt some of the same suggestions.

- Make a list of two or three friends/family that you would like to have on your support team. Choosing someone with a medical background is helpful, but not crucial. Meet together to talk about what you want them to do.

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- As a group, decide who will go to which medical appointments. Record them on a shared calendar (Google calendar, Outlook.com, etc.). You can also share this calendar with others, such as family, to keep them up-to-date.
- Audio record your medical visits so all team members can hear what has been said and stay up-to-date.
- Have the person who accompanies you to medical appointments take notes, particularly the main facts you need to know, so you can refer to them when you feel ready. After a medical appointment, the team member is to ask if now is a good time to tell you three pieces of information. If you hear one piece and that's all you can handle, tell them that's all you can listen to right now. Let them know that you are feeling overwhelmed because that gives the helper clarity as to why they need to stop. The helpers need to know these "rules" ahead of time.

To help unlock the freeze reaction, touch or movement are essential.

- Wrap yourself in a cozy blanket. Some have found weighted blankets particularly helpful.
- Be hugged by someone you trust and love
- Have your hair washed
- Take a walk in nature
- Get massaged
- Dance
- Sit with a pet
- Ride a bike
- Dig/plant in the dirt
- Fish, as casting and reeling movements are calming

1. Throughout the stages of a medical crisis and more, we move back and forth between the three modes: fight, flight, and freeze. Most of us, though, tend to have a "go-to" approach. Which is your primary one?

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2. Our relationships with family, friends, and colleagues vary. Identifying what type of support you need from specific people allows you to let them know. When you are in your primary mode of reaction (fight, flight, or freeze), what kind of support do you need? My primary mode is ____________. When I am in this mode, I need...

| I need this kind of support | From this person |
|---|---|
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3. When your stress is heightened, what mode (fight, flight, freeze) do you move into as a reaction? ________________________mode. When I am in this mode, I need…

| I need this kind of support | From this person |
|---|---|
| | |
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## 4-What Do I Do Now

> *Trust your doctors. If you don't trust them, you will not fare well. Make sure they discuss everything with you and that you understand what is happening.  If they don't talk to you or answer your questions, find another doctor. –SR*

### Choosing a Physician

Medical needs can start with one physician and lead to another. Each step along the way, it is important to have a medical team you feel you can work with. We are putting our lives in the medical team's hands, so finding the right fit is imperative. As our minds spin with details and emotions, it is particularly challenging to seek out a doctor. The right fit is a combination of knowledge, experience, and personality that suits us. Steps that can be used to find a physician include:

- Talk to your regular physician/gynecologist/cardiologist, or your child's pediatrician, and ask for recommendations
- If referred to a specific clinic, ask a nurse if one provider is better at meeting the qualities in a physician that are most important to you
- Call local hospitals and ask for referrals
- Investigate medical universities and their physicians with specific specialties
- Contact organizations (e.g., American Heart Association, American Cancer Society, National Institute of Health, Brain Trauma Foundation) to see if they have recommendations

Finding medical professionals you want to work with is one topic in which Google can be your friend by providing pointers to jump-start your search. As of this writing, U.S. News and World Report has an article called "How to Choose the Best Specialist Doctor."[1]

*I was at work and got a phone call from my gynecologist who said my test came back and that I needed a hysterectomy. He was very matter-of-fact, cold, and had no emotion in his delivery. I ended up firing him. I knew I needed someone else. I researched and asked around and got the name of Dr. Edward Weiser, who was amazing. We were around the same age and hit it off personality-wise. He was always attentive and his bedside manner was good. –DH*

*The doctor who performed the biopsy called and with a blunt statement announced, 'It's cancer.' It hit me like a lead balloon and I was extremely upset. It took me over a week to even discuss it with family. –KM*

*Ask around and seek the right doctors. –JZ*

*Have a doctor you absolutely trust. –NA*

*Get a second opinion. –GW*

*Some people wondered why we were content with the diagnosis and treatment plan given by our medical team and why we didn't go for a second or third opinion. We felt we had the best. We didn't want our choice to be questioned. –NL*

*Listen to your doctor and if you don't like the doctor, find another one. –KM*

*Go to doctors you trust and feel you can get along with. –MM*

## Expenses

As the rollercoaster climbs up the hill, so do expenses. Expenses, missed work, and insurance coverage add stress to an already challenging time. At this stage, questions about cost will swirl through your mind. Writing down your questions will give you a starting point as to what information you need. How much is this going to cost? Is my insurance going to cover this? How much will I have to pay out of pocket? What if I can't work?

A Stress in America report in 2018 revealed that health-related issues are stressful for Americans regardless of a family's household income. The study found that 64-69% of Americans feel stress about the cost of health insurance and 56-57% experience stress regarding medical bills.[2]

*The cost of all the surgeries and treatments is hard. –LE*

## I Need to Know More Than Treatment

Moving through a medical crisis requires new skills and information. Finances, law, insurance, and benefits become our new language.

### Financial Impact

> *People don't talk about the financial impact mental health disorders can have on a family. It costs a lot of money. Getting help, particularly mental health services, is costly. Insurance doesn't cover much and the end of treatment is not in sight.–*
> *KW*

The financial impact of an illness, accident, or chronic condition creates hardship for many families and leads to greater stress and worry.

The National Cancer Institute's information in 2022 calculated the average cost of medical care and drugs tops $42,000 in the year following a cancer diagnosis. Some treatments can exceed $1 million. About 1 in 4 have declared bankruptcy or lost their home to eviction or foreclosure. Other research shows that patients from minority communities are more likely to experience financial hardships caused by cancer than white patients, reinforcing racial disparities that shadow the U.S. health care system. [3]

The Alzheimer's Association lists the following costs in 2022.

- Median costs for long-term care services 2022
  Long-term care services include home- and community-based services, assisted living and nursing home care.
- Home care: A paid non-medical home health aide is $28.64 per hour and $1,145 per week (assuming 40 hours of care per week).
- Adult day services: $83 per day.
- Assisted living facilities: $4,774 per month or $57,289 per year.
- Private room in a nursing home: $315 per day or $115,007 per year.
- Semi-private room in a nursing home: $276 per day or $100,679 per year. [4]

Mental health and substance abuse coverage is significantly below that of physical health coverage despite mental health and substance use disorders are among the top ten leading causes of death in the U.S. and the leading cause of Years Lost to Disability (YLD). The deficient insurance coverage for mental health and substance abuse care places a burden on families. An hour-long traditional therapy session can range from $65 to $250 for those without insurance, according to therapist directory GoodTherapy.org.

A more severe diagnosis, of course, carries heavier lifetime cost burdens. A patient with major depression can spend an average of $10,836 a year on health costs. [5]

We might all hope we have prepared for such expenses, but the fact is, few are. Additionally, there is little to no way to predict what situations might befall our families.

## Navigating Insurance

Often we don't know much about our insurance policy until we need to use it. The terminology and questions to ask can feel overwhelming. Others can help with this task. Having a trusted loved one gain an understanding of insurance coverage, how to file the claims, and record impending expenses can be a significant help. Company Human Resource departments typically have someone who understands the health insurance the company provides and can be a contact person to help you understand your coverage. Most doctor offices and hospitals have staff that investigate a patient's insurance coverage.

The first steps include directly contacting your insurance claims department. In speaking to them, it helps to know your diagnosis and the terms of pre-existing conditions and preauthorization.

Pre-existing conditions are health problems, such as, asthma, diabetes, or cancer you had before the date that your health coverage began. According to HealthCare.gov, all marketplace plans must cover treatment for pre-existing medical conditions. No insurance plan can reject you, charge you more, or refuse to pay for essential health benefits for any condition you had before your coverage started. Once you're enrolled, the plan can't deny you coverage or raise your rates based only on your health. Medicaid and the Children's Health Insurance Program (CHIP) also can't refuse to cover you or charge you more because of your pre-existing condition. Insurance companies can't refuse to cover treatment for your pre-existing condition or charge you more.[6]

Per HealthCare.gov, your health insurance or plan may require preauthorization for services before you receive them, except in an emergency. However, preauthorization isn't a promise your health insurance or plan will cover the cost.

> *Double-check what your insurance is or isn't covering and double-check your preauthorization. Don't let anyone convince you to "sign now" to be treated and get authorization later; you can be responsible for thousands of dollars. I work in medicine, and the insurance situation during my illness was a nightmare. I often wonder what happens to those who are not familiar with navigating insurance. – BK*

*It really helped to have my husband check out our insurance coverage details so I didn't have to. –CS*

## Financial Ideas to Explore

Reach out to an accountant to learn what expenses are deductible and the best way to pay for some expenses given your financial situation and insurance coverage. Some companies offer Health Savings Account (HSA) for their employees to contribute to. Talk to colleagues and/or Human Resource personnel to learn about your options.

Some communities and faith-based organizations offer financial support to pay for specific needs, help bridge gaps between paychecks, and other needs due to a medical situation. In my community, there is a nonprofit organization called the Loan Closet that has medical equipment (e.g., wheelchairs, walkers) for citizens to borrow for no fee. Residents can borrow the equipment for their own use or for visiting family members.

Talk to your doctor about problems with finances. Many offices have a staff person who can advise you about payments, relief, and community resources.

If your loved one is hospitalized, hospitals have social workers who can guide you concerning finances.

Reaching out to pharmaceutical companies can be beneficial. Some have programs to help pay for treatments.

Some medical situations interrupt or permanently end one's work life. When patients can't work, they may qualify for disability through a personal policy and/or Social Security. Meeting with an attorney who specializes in disability law can guide you through filing for disability through the Social Security Administration.[6] There are specific standards and information needed for Social Security to make a decision, and if you don't include all of the needed information, you can be denied — and it is more difficult to appeal than apply. Most attorneys who do this type of work do not require a retainer but are paid from your successful claim. When the Social Security Administration approves your claim, they pay the attorney's fee out of your first check or two. If coverage is denied, the attorney isn't due payment (make sure that is in the contract you have with the attorney).

Handling the search for financial support, navigating insurance claims, and filing for disability can be overwhelming on top of an already devastating situation. Many people want to help and having a friend or family member you trust take on these roles for you is a huge help and a good way they can provide support.

## Important Laws

Recent legislative changes may provide you with some relief and support. As of January 2023, thirteen states and Washington, DC passed laws to help caregivers through paid and unpaid leave options. Thirty-seven states, two territories, and Washington, DC enacted the CARE Act (Caregiver Advice, Record, Enable) which provides support for family caregivers as loved ones enter the hospital or return home. Relevant articles include:

- https://www.aarp.org/content/dam/aarp/ppi/2018/08/breaking-new-ground-supporting-employed-family-caregivers-with-workplace-leave-policies.pdf
- https://www.agingcare.com/articles/employee-benefits-for-working-caregivers-149872.htm
- https://www.dol.gov/general/topic/benefits-leave/fmla
- https://www.usagainstalzheimers.org/sites/default/files/2018-09/A_New_Frontier_In_Paid_Leave.pdf
- https://www.newamerica.org/better-life-lab/reports/lifting-barriers-paid-family-and-medical-leave-men-united-states/introduction/
- https://www.shrm.org/resourcesandtools/hr-topics/benefits/pages/starbucks-caregiver-benefits.aspx
- https://qz.com/work/1662928/the-case-for-giving-paid-leave-to-all-employees-for-any-reason/

*It was helpful to have someone with power of attorney to help pay bills and fight for coverage with insurance companies. My sister, Chris, did this for our brother. He was often overwhelmed and needed help with that.–KL*

*We found it incredibly helpful to educate ourselves about schizophrenia and to connect with other people who had loved ones dealing with mental health challenges. Our education included taking NAMI's (National Alliance of Mental Illness) Family-to-Family course. After completing this course, a group of us from the class continue to meet once a month to provide an ear and offer what support we can for each other. We've been meeting once a month for about six years now.–MCM*

Most of us have little knowledge about certain diseases or traumas until we are thrust into the situation. Names of less commonly known diseases, treatment options, and medications quickly become as familiar as our own names. We receive an education we never thought we would need.

While many who have dealt with medical crises recommend arming themselves with information, not everyone wants to know or learn about all aspects. Having knowledge about the crisis can lead some to experience increased anxiety, worry, and confusion. Therefore, it is important to know what is important and will help you. As with so much of this journey, the choices are personal and depend on what you need and want.

## Workbook Chapter 4 What Do I Do Now

Here's one way to evaluate if you need or want a specific piece of information about your situation.

Step 1.

| Will this information help me | Yes | No | Maybe |
|---|---|---|---|
| Prepare myself | | | |
| Understand diagnosis and treatment | | | |
| Learn about the course of treatment (what will happen?) | | | |
| Understand the side effects of medication, treatment or illness | | | |
| Be a better advocate | | | |

Step 2.
After you think about the above areas, move to the next layer. Identify what you *want* to know, who to ask for the info, and who will ask. The latter column is helpful if a group of people is working together as caregivers. Together, you can determine who will gather what information and report back.

| What I want to know | Who can I ask | Who will ask |
|---|---|---|
| | | |
| | | |
| | | |
| | | |

| | | |
|---|---|---|
| | | |
| | | |

Step 3.
A final area is to acknowledge what you don’t want to know. Maybe you don’t need to know it and don’t want to spend time on it. Maybe you don’t want to know it now. Maybe you just don’t want to learn about it at all.

What I don’t want to know

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[1] https://health.usnews.com/health-care/patient-advice/articles/2018-01-11/how-to-choose-the-best-specialist-doctor

[2] https://www.apa.org/news/press/releases/stress

[3] https://www.npr.org/sections/health-shots/2022/07/09/1110370391/cost-cancer-treatment-medical-debt#:~:text

[4] https://www.alz.org/help-support/caregiving/financial-legal-planning/planning-for-care-costs#:~:text

[5] https://www.cnbc.com/2021/05/10/cost-and-accessibility-of-mental-health-care-in-america.html

[6] https://www.healthcare.gov/coverage/pre-existing-conditions

## 5-To Tell or Not to Tell

*Telling my children and family was the hardest part of my experience. –SR*

As we move through our days, most people don't think about their health, but when a medical crisis strikes, it takes center stage. Our weeks are infused with doctors' appointments, treatment, time off from work, and for some, changes in appearance. Early in the process, we are confronted with decisions about whether or not to tell others about our situation, and how to do so.

You can actively prepare what you want to say to others about your situation. You might choose to tell some people more details than others. That's okay; remember, it's your choice. Have prepared responses for questions that might be asked ("That's not something I want to talk about," "I don't know the answer to that," "I'm confident in my doctor.").

Telling others at work is a complicated issue for many. Sometimes it's necessary to take time off from work. When talking to a supervisor, it helps to focus on specifics (such as the time needed for appointments or leave of absence), as it keeps the conversation focused on work, not emotions.

*Telling my family was the most difficult part. I did not want them to worry about me. For some crazy reason, I didn't want to discuss it and was angry about the entire dynamic. It made me feel "vulnerable and old" for the first time in my life. –DP*

*My mother was dying from the same disease I was just diagnosed with. I briefly considered not telling her about my diagnosis. In the end, I decided to tell her. My friend said it best, "Would you want to know if your son was sick, even if you were on your deathbed?" –LO*

*My boss had warned "lovingly"' that she'd fire me if I showed up at work during my treatment, but I convinced her it was good for my mind, body, and soul. –BK*

*I didn't want to tell anyone at my work about my cancer and treatment. I didn't want clients or colleagues to know. I just had to hope I wouldn't lose my hair. –BS*

### **Cindy's Journey** ***What Should I Say?***

Sigh. This is going to be hard. What do I say to my kids? They are all in their late 20s and early 30s, independent in all meanings of the word, but they are "my kids." Funny thing about being a parent — their heights might climb above yours, their paths take different turns, and they might have babies of their own, but no matter how tall, different, similar, or old they are, they are our babies. Our first instinct is to protect. I couldn't imagine telling them about my diagnosis, particularly since the outcome was so uncertain.

And so, Ben and I talked and talked and talked about what to do. My mother-bear instinct was to keep going as if everything was normal, but his logical, steady mind took over, presenting me with the other side, “Don’t you think they would want to know?” He got me there. Yeah, they probably would. We developed a plan on how to tell our adult children.

We decided to call each of them separately. Ben would talk and I would be on the line. We thought calling them would be better than seeing them in person because witnessing their faces as they received the news felt like too much — maybe for them, but definitely for me.

We called on a Sunday night. He told each one I was diagnosed with a blood cancer called multiple myeloma. He explained about the plasmacytomas, the cause of my fractured vertebra, and back pain. He gave them a brief outline of what was to come, including radiation and chemo that would be done locally with Dr. Lee at the helm, but also that we would be going to Boston to see Dr. Anderson, one of the leading experts in the multiple myeloma field. After meeting with Dr. Anderson, we'd know even more.

It wasn’t easy. Ben’s voice cracked with emotion. I could hear and feel the shock in their hearts. I reassured them that I was doing okay and would do what I needed to. We hung up the phone and after the fourth call, I cried.

## 6-What Helps and What Doesn’t upon Hearing the News

I believe most people have good intentions. When hearing about someone going through a challenging time, most want to reach out, say the right words, and offer help. In doing so, some folks just naturally hit the right mark, while others fumble around and put their foot in their mouth. Other people act as if nothing has happened because they aren’t sure what to do. They figure saying nothing is better than saying something wrong.

While we all have individual preferences, there are common actions that can be helpful. The tips below may help pinpoint what is most useful to you.

### What Others Have Found Helpful

Patients and loved ones have a lot to do and digesting and responding to even the kindest of messages can be a lot to manage. In written communication, saying “no reply is needed” allows the person to accept the message without the burden of responding.

> *Text, email or leave a message to say the person is thinking of me and that there was no need to call back. –JN*

Acts of faith and positive intention can give a sense of comfort. Receiving a letter with the names of the people who are praying for a person is particularly comforting because it shows the number of people who have come together to offer support.

*My parents' church placed me on their prayer list, and I got a letter with all their signatures on the letter each week. I knew that people were praying for my recovery and me.*
*I truly feel that it helped me in my healing. –DH*

Sending out updates to your supporters is less burdensome than repeating the facts and answering each person's questions. It decreases the chance that you will be confronted with questions you don't know the answers to. It also is a benefit for everyone to receive the news at the same time, so others don't hear it from someone else who might misconstrue facts in the retelling. Hearing the news via email allows the receivers to digest the information before responding. The most important response is a sincere one.

*When my wife was diagnosed, I sent out an email to my friends to let them know what was going on. It was helpful when they responded to me by email or in person that they wanted to be there to help, and they sincerely meant it. –BAS*

### What Not to Say

*I hated it when people said, "Oh, you'll be fine."–DH*

*"Everything will be okay." How could they know my son would be okay???–LVB*

Well-meaning comments can hit us the wrong way. Whatever your reaction, it is okay. These are choppy waters we tread and there is no wrong way to feel.

At a time in our lives when we are faced with unknowns and our minds are filled with what-ifs and different scenarios (including death), to say, "You'll be fine" feels dismissive — as if what we are going through isn't a big deal.

Comparing the diagnosis to another diagnosis is disrespectful of what the person is going through.

*"At least it's not melanoma."–CS*

*"It's only benign." Benign tumor in the brain is still a big deal.–JZ*

While the loss of a child is considered the greatest loss one can experience, any loss is significant. When losing a parent, we are faced with losing part of our childhood. Such an impending loss sparks memories, early grieving, and pain. Disregarding the impact of the loss of someone who is older discounts the role that person has played in the person's life.

*“Well, he’s had a long life.”–TS*

Everyone moves at their own rate through their crisis. Sometimes, the pathways toward treatment are clear and defined. Other times, each step depends on how the prior step goes. When people ask a lot of questions, it can increase anxiety, worry, and feel intrusive.

*The worst of all was all the questions! It only increased my anxiety and satisfied their curiosity.–JN*

It is truly difficult to know how someone feels. We can imagine how someone feels. We can empathize with how someone feels. When in the same situation, we may have similar feelings, but everyone is unique, and saying, “I know how you feel” can give the person a sense of not being understood.

*I know just how you feel.–MR*

Upon receiving a diagnosis, most experience shock, and to hear that “it could be worse” can increase anxiety and incite anger. Most of the time, this is a true statement, but it is not a helpful one.

*It could be worse.–RS*

### Cindy's Journey How Are You? What's Wrong with That?

I've spent hours upon hours in my oncologist's office. An oncologist's office isn't the happiest place to be. Everyone there has something they are dealing with.

As I look around the room, I wonder how many of these people will be alive a year from now? Five years? Ten? And, then a medical professional calls someone's name breaking my mortality questions. As the patient ambles toward the door, he is greeted with "How are you?"

My mind screams with, “How do you think they are?” If they are coming to your office, chances are they aren’t doing well. They are scared, angry, sad, hopeful, discouraged, and a mass of other emotions.

PLEASE, I want to shout, greet patients with, “It’s good to see you”.

## 7-Figuring It Out

### I Don’t Know What I Feel or Need

> *I just got a position as a professor in a new program at the university where I work. I was determined not to miss a day of this exciting position, cancer or no cancer. That's what I need. – RW*

In order to know what you are experiencing, it can be helpful to write yourself a letter. Start the letter with something like, I can't believe this is happening. It is…Beginning with "It is…" helps spark the brain into describing what is occurring. The feelings that sit beneath the surface can emerge in your writing. This can be an emotional process, so it's important to give yourself uninterrupted time to write.

## Workbook Chapter 7 Figuring It Out

**I can't believe this is happening. It is…**

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Once the feelings have surfaced in the letter, put the letter away for a few days or a week, and then pull it out. Reading through the letter, you may find there are some other ideas you would like to add.

The next step is to write what it is you want/need. This can start out with the ideas below. Again, it's important to give yourself enough uninterrupted time to work on this.

**I wish…**

---

**I want…**

---

**I need…**

---

After time has passed, read over what you wrote. Take what you wrote and determine if there is something or someone who can help you meet a want or a need. Look at the list and put the name of the people who can respond to each need. For example, there were times when I wanted to be distracted by the reality of what I was going through. I found that being with my grandchildren was a distraction that took me away from the tough times. Playing games and interacting with them required my full concentration. The result was joy. See what desires surface for you and how they can be fulfilled.

| Need | Who or What Can Meet My Need |
|---|---|
| Example: distraction | watching movies; playing a game with child; talking to my friend Leslie |
| | |
| | |
| | |
| | |
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| | |
| | |
| | |

## My Emotions

As we navigate through these uncharted waters, using our self-awareness can lessen confusion and frustration. Below are questions based on the information presented. Answering these questions can assist you through this process and ease some distress, whether you are the identified patient or part of the support team.

## Workbook Chapter 7 Figuring it out *My Emotions*

1. Throughout this initial stage, as well as subsequent phases, we move back and forth between the three modes: fight, flight, and freeze. You identified your primary reaction mode in Chapter 3. To look further, write which reaction (fight, flight, freeze) do you identify as your primary reaction mode?

______________________________

2. Our relationships with family, friends and colleagues vary. For example, we may be receptive to a hug from one person, but not another. Identifying what type of support you need from specific people allows you to let them know. When you are in your primary mode of reaction (fight, flight, or freeze), what kind of support do you need? My primary mode is ____________. When I am in this mode, I need…

| I Need this Kind of Support | From This Person |
|---|---|
| | |
| | |

| | |
|---|---|
| | |

3. When your stress is heightened, what mode (fight, flight, freeze) do you move into as a reaction? ______________________mode. When I am in this mode, I need…

| I Need this Kind of Support | From this Person |
|---|---|
| | |
| | |
| | |
| | > |

When a medical crisis occurs, we are propelled down a path for which we are unprepared, never knowing how long it will be or how it will end.

Medical teams guide us through the physical aspects, but we are left on our own to understand the emotional and practical impacts as our lives change. By understanding what happens in our brain and the common emotions experienced during the initial stage, we can better determine what support will help us and how to make decisions.

Moving through the journey causes our experiences to change. There will be times that are more challenging, and there will be moments when life feels calmer. Through it all, trust yourself and surround yourself with those who care.

### Cindy's Journey When Are You Leaving?

For the first 10 years of my life, I was fortunate to live near my grandparents and great-grandparents. Memories are peppered with games of Tiddlywinks, dominos, and cards with my grandmother, along with family cookouts. My grandparents' home was perfect for visiting grandchildren, as they had a creek flowing through their backyard, a pond in which to swim and catch frogs, and a path leading to a Dairy Queen. Summer days couldn't get any better.

Just prior to entering fifth grade, my father's job took us from the close proximity of extended family in New Jersey to a new adventure in the suburbs of Pittsburgh. While missing family cookouts and swims at my grandparents' place, I embraced their visits to our new home. On one of their visits, as soon as my grandparents arrived, I quickly asked, "When are you leaving?"

My seemingly impolite question was asked to set my expectation of how many days I could enjoy them being there. Later in the day, my mother instructed me that there was a better way to ask such a question ("How long are you able to stay?"). Ok, lesson learned.

These days, I have an unwanted guest. No matter what I am doing, this uninvited visitor demands attention. Taking walks while gazing at trees and feeling the warmth of the sun, my mind focuses on what medical appointments are upcoming. Playing with grandchildren and reveling in their developing personalities, my attention is pulled away to wonder if I will live to see them into their adulthood. No matter how hard I try to dismiss this visitor, it remains, inserting itself in all the moments of my days.

As the calendar flips from one month to the next, I focus on my visitor, demanding to know, "When are you leaving?"

## 8-You Are Experiencing Trauma

When we experience a medical crisis, we look to professionals for guidance. They make recommendations based on knowledge and experience; they share opinions about surgery, medication, rehab, treatment, or entering a trial. In a medical crisis, we are impacted by more than the physical aspects, yet little is said as to how our way of life and emotions might be affected. During the treatment process, our system undergoes massive changes. Our brains and emotions react as our bodies struggle to regain health and balance.

Understanding what is happening can provide solace and comfort as we search for ways to cope during the treatment stage of the journey.

*I was 23, and so happy driving down the beltway on my way to pick up my new pet chinchilla, when a nine-pound piece of metal from a truck hurled through my windshield, penetrating my skull. At Shock Trauma, I was diagnosed with an uncountable number of fractures around my frontal bone, eye socket, cheekbone, jaw, and teeth. All the sinus cavities and most of the muscles on the upper left side of my face were injured. Excessive swelling loomed around my* *head. Blood was everywhere. I vomited up blood that kept going into my stomach along with my teeth. My life was forever changed. –CK*

Human beings are resilient, in part because we focus on what is around us that we can control. If we experienced all of what is happening in the world, near and far, few of us would be able to function. Our minds, hearts, and souls would be overwhelmed, rendering us immobile, unable to make decisions, wanting to retreat and run for cover. Our ability to screen out what we can't handle is remarkable, but when we are thrust into a medical crisis, the safety net is removed, and trauma reactions set in.

When we think of trauma, our minds flip to scenes of war, violence, abuse, or the death of a loved one. The traumatic nature of these events is easily understood. When we receive a life-threatening diagnosis or experience, it sets off specific neurological and emotional reactions similar to more traditional traumas.

*After two surgeries and prolonged treatment to combat my mother's cancer, I wanted to get back to normal. After all, I was nine years old. Unfortunately, life did not return to normal because my parents separated and divorced shortly afterwards. I was thrown from one trauma straight into another. –AB*

## Socially Acceptable Trauma

As a society, we struggle with what we can't control. Certain illnesses and situations become taboo to discuss. We retreat in silence leaving others feeling unsupported and isolated which fuels the trauma reaction brewing within. It wasn't until the 1990s when emerging grassroots organizations and advocacy made it more acceptable to talk about cancer diagnoses.[1] The silence was even more striking during the AIDS epidemic. Individuals and families in desperate need of support were met with misunderstanding and exclusion. Today, we continue to be challenged by understanding and discussing physical and emotional health. To have a mental health diagnosis is often viewed as a personal weakness. Even our health care system discriminates against mental health care by covering treatment at a lesser financial rate than physical health care.

*My wife's mother has cancer. We don't know what her prognosis or treatment is. They are the type of family that doesn't discuss things. We don't know what to do to support them. They shut every conversation down. –TS*

## Cindy's Journey *Silence is Not Always Golden*

When I was sixteen, I met Renee. We went to different high schools, but we worked at the same McDonald's. McDonald's was my first job outside of babysitting for neighborhood children, and I loved it. Driving to work, receiving a paycheck, and making new friends fed my emerging independence.

Renee's mother, Velia, had been ill for quite a while before I met Renee. I didn't know what was wrong with her, and neither did Renee. Nobody would tell us. We just figured whatever was wrong, she would get better, despite being bedridden and in pain.

One day, I went to Renee's to pick her up so we could go to work our shift at McDonald's. While Renee was getting ready, her mother called me into her bedroom. The curtains were drawn, and a thin shard of light filtered into the room from the hallway. Velia took my hand and in a trembling voice implored, "Be strong for my Renee." My teenage self tightly gripped her hand assuring her I would, without truly comprehending what was happening.

Velia died of breast cancer a few weeks later.

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[1] Osuch, J. R., Silk, K., Price, C., Barlow, J., Miller, K., Hernick, A., & Fonfa, A. (2012). A historical perspective on breast cancer activism in the united states: from education and support to partnership in scientific research. Journal of Women's Health, 21(3), 355-362. doi:10.1089/jwh.2011.2862

## 9-How Your Brain and Body Deal with Treatment

People fascinate me. It's one of the reasons I enjoy being a psychologist as I seek to understand why people react the way they do. As unique as individuals are, patterns typically emerge. Recognizing patterns is helpful to understand why we feel the way we do and how our reactions are experienced by others in similar situations.

As treatment suggestions are presented by medical teams, many of us feel a sense of danger and fear about what is to come. This sense of danger sets a hardwired response in our autonomic nervous system into motion, spurring our minds and bodies into that all-too-familiar fight/flight/freeze response that we began to experience at the onset of the medical crisis.

Hormones, such as adrenaline, are released. Adrenaline is often mentioned when talking about athletics and other performances. As an athlete runs onto the field, a speaker steps up to the podium, or a dancer takes stage, adrenaline levels rise, preparing muscles for exertion and narrowing focus to the task at hand. These shifts in hormones allow us to do what we need.

Just like the caveman encountering that mountain lion, stepping onto the field or stage spikes adrenaline, and we experience specific changes in our brains and bodies. Treatments and side effects become our mountain lion. As treatment options are presented, our adrenaline surges, muscles tighten, heart pounds, breath quickens, and sweat breaks through our skin.

For some of us, the fight mode emerges and shifts us into seeking out options and evaluating the pros and cons of the different options. Flight mode moves others into not wanting to decide, ignoring and/or heavily relying on others' opinions or asking the medical team to make the decision. In the freeze response, the brain interprets the treatment choices as dangerous, and the surges in adrenaline spark feelings akin to stage fright, rendering a sense of immobility.

## Fight Mode

We prepare and get our mind set on fighting whatever comes our way. Those in fight mode acquire information and resist others' opinions because they seek to have some control in an out-of-control situation.

*I needed to have my prostate removed. I asked my doctor a thousand questions. I want to know everything. My wife and I both took notes. When we got home, we compared our notes and discussed every piece. I mapped out when I could return to work based upon the doctor's projections (likely a month) and when I could start golfing again (maybe in six weeks, but cart only). I want to get this over with. –UK*

*My brother was diagnosed with multiple myeloma, a cancer we had never heard of before. I went into education mode and found the International Myeloma Foundation website. It was full of information. He and I went to a patient/family seminar. I tried to find out as much information as I could. There had to be a way to beat this.–KL*

## Flight Mode

The mechanisms of the flight response create an uneasiness, and this imbalance moves us to want to heavily rely on others' opinions or ask the medical team to make the decisions.

*A friend of mine has the same doctor and is having his prostate removed the same week I am. As we talked, it is clear my friend doesn't grasp all that is involved; he's planning a European hiking trip for three weeks after his surgery. I peppered him with questions about whether he talked to the doc about his plans. Did he know he is going to have a catheter? Did he take notes when the doctor was talking? He started to walk away and turned to me and said, "I just want to go in, have the surgery, and get on with my life. I don't want to hear all the particulars." –DF*

On the other hand, some of us choose not to pursue treatment and this does not mean we are necessarily in flight mode. To others, that choice might look like a flight response, but can be a deliberate, thoughtful decision.

*My sister didn't want any treatment when she received her diagnosis. When she finally talked about her diagnosis, I learned she was first diagnosed years before. –KG*

## Freeze Mode

In the freeze response, the brain interprets the treatment choices as dangerous, and the surges in adrenaline spark feelings akin to stage fright, rendering a sense of immobility.

*I became so anxious; it was like being in shock.–SH*

Knowing which reaction you tend towards helps you avoid being stuck in one of them. Reviewing the different ways to deal with fight, flight and freeze can help you work through these reactions during treatment.

## 10-Treatment Side Effects

*Side effects from the treatment were the hardest parts for me. The sensations caused by the tumor and treatment included neuropathy, double vision, fatigue from morning to night, disorientation, fear, and inability to think positively. –MF*

Medical advances over the years have allowed many to heal, feel less pain, and manage symptoms. Treatment can be beneficial, but it can also create side effects that further complicate our journey. How your brain and body respond to treatment can increase the trauma of this journey. We'll look at "chemo brain," hair loss, fatigue, eating, digestive health, and more.

## Chemo Brain

> *Chemo brain. That term frustrates me to no end. In conversation with someone, I struggle to find the word I want to no avail, so I quickly apologize to the listener. "Don't worry. It's just chemo brain," comes the response. Don't worry? Are you kidding me? With everything else — bald head, reduced energy, massive life changes and now this! Don't worry? Well, I am worried. I don't like not being able to think and remember like I used to. I hate it. –CS*

We brace ourselves for the physical impact of our treatment, but we are often unprepared for the neurological and emotional results of treatment and the accompanying stress, such as chemo brain. Which side effects come from chemo and which from illness and stress are uncertain. Some medical personnel reject the idea of chemo brain, while others recognize the impact is real.

Todd Horowitz is a leading researcher at the National Cancer Institute. He shares some of his thoughts about chemo brain in an article about his work in Cancer Today magazine.[1] Dr. Horowitz explains that the technical term for what we refer to as chemo brain is cancer-related cognitive impairment, or CRCI. Researchers report that CRCI is more complicated than just the impact chemotherapy has on the brain. CRCI seems to affect many cancer patients even before they receive chemotherapy, regardless of the type of chemotherapy they get. Some patients treated for cancer don't get CRCI symptoms. Horowitz supports what many of us understand: that a medical crisis itself is stressful, and the stress and trauma of the journey affects our ability to concentrate and remember things. Understanding that the stress and trauma of a medical crisis significantly contribute to "chemo brain" explains why some of our loved ones, and even those patients who have not received chemo, experience similar symptoms.

Typical "chemo brain" symptoms include:

- Forgetting things that are usually easily remembered
- Trouble concentrating (can't focus, short attention span, may "space out")
- Trouble remembering details, names, dates, and sometimes larger events
- Trouble multi-tasking (talking on the phone while cooking and not losing track of either)
- Taking longer to finish things (disorganized, slower thinking and processing)
- Word-finding difficulty (unable to find the right words to finish a sentence)

When we complain to friends about this, many comment they experience it, too, and that it is just a part of aging. However, we know the difference. We search longer for words and ideas than we did a few months ago. We make mistakes we rarely would. We search for the ability to concentrate on work, even when doing something simple.

*Medications for physical issues have a definite impact on mental processing and stability. –GM*

*Even though I was cleared to drive, the weakness and mental fog made me unstable and unsafe to drive. –BK*

*As a child, I was diagnosed with Auditory Processing Disorder. This makes it difficult for me to find what words I want when I'm talking. Add that to the impact on my brain from the accident, and I struggle to communicate. –CK*

### Cindy's Journey *Oh, My Brain*

I wasn't a top student; that was my sister, Debbie. She was (and is) the "brain" in our family. She loves to learn, read, and study. One summer, when she was about 12 years old, she sat at the top of our steps and read the encyclopedia, from A to Z. Admiring her so, I pulled out the A volume, and after reading the entry on abacus, I knew that pathway of acquiring knowledge wasn't for me. And so it was set: in our family, Debbie is the smart one.

One subject I did enjoy and excel at throughout elementary school was spelling. I know, it's not a lofty or conceptual skill, but I liked spelling tests. I always knew what would be on the tests, so I could easily prepare. Monday pretests were my victory. Correctly spelling all the words on the pretest led to being exempt from weekly spelling assignments and the Friday test. More importantly, it meant being included in special assignments. Such special assignments involved making large maps of the different continents and their countries. South America was my favorite. Drawing maps and labeling countries, capitals, and geographic features were not only enjoyable, but I learned more from making those maps than I would from the weekly spelling grind.

It’s been decades since I have taken a spelling test, but it has remained a natural strength for me — until now. Today, I sent out an email to colleagues. In it, I made two spelling errors I didn’t catch, even though I read over the email before I sent it. One error was a homophone; I wrote whole and meant hole. The other word was hearsay and I wrote heresy; sure, lots of the same letters, but wrong. One of the colleagues pointed it out and blamed it on autocorrect. I should have let it go at that, but my angst and embarrassment at making such a public mistake propelled me to call it what it was: chemo brain.

I hate it. My brain gets foggy. I mix up my words. I forget things that sit in the back of my mind typically ripe for recall. I know when I am not thinking clearly, and my concentration feels layered with a blanket of haze.

Although I’m not “the smart one” in our family, I really like my brain. It helps define who I am and has allowed me to be successful. Now, it’s different. It is said that chemo brain is temporary, but meanwhile, what do I do? What can I do to reignite my thinking? I don’t have the answers to the questions. I am left with frustration and self-doubt.

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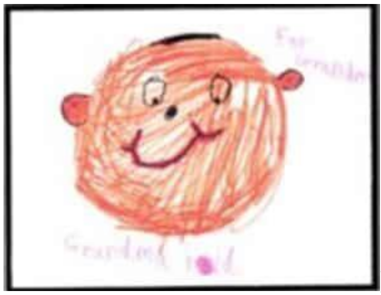
## Losing Hair

> *There are studies that show that for many women, losing their hair is worse than losing a breast. That's because you can conceal the loss of a breast, but hair loss is so obvious and apparent. –Marisa Weiss, M.D., Chief Medical Officer, Breastcancer.org*



Losing one’s hair due to treatment is often one of the most challenging aspects of treatment. It is an outward sign to the world, letting it know what is going on within your body. For many, losing hair spikes a privacy issue. *Bald Grandma drawn by granddaughter ARG*

Radiation causes hair loss on the part of the body treated because hair follicles are very sensitive to radiation. Most notice hair loss at the treatment area about three weeks after the start of radiation. Radiation to the brain, often used to treat metastatic brain cancer, usually causes complete hair loss on the head.

Chemotherapy is designed to destroy cancer cells that are rapidly dividing. Chemo doesn't know the difference between cancer cells and healthy normal cells, so during chemo, some healthy cells are destroyed, causing side effects. The healthy cells most frequently affected are those cells that also quickly divide. These cells include blood cells, skin cells, cells in the mouth, stomach, bowel — and hair follicles.

Hair follicles are some of the fastest-growing cells in the body. Under normal, healthy conditions, hair follicles divide every 23 to 72 hours. As chemo targets rapidly-dividing cancer cells, it also destroys those quickly-dividing hair cells.

Hair loss can be gradual or dramatic. It's not unusual to find clumps of hair in the sink, in a brush, or on a pillow. Hair loss isn't restricted to hair on the head; some chemo treatments cause the loss of eyebrows, eyelashes, pubic hair, and hair on legs, arms, and underarms. My 80-year-old father-in-law told me he had lost his hair everywhere. In a dejected tone he said, "It makes me feel like a young boy and not in a good way."

Even knowing we will lose our hair; it is often startling when it occurs. To help adjust to the change, some suggest purchasing a wig before your natural hair falls out, so the stylist can match your hair color and style. My nurses recommended I get my shoulder-length hair cut into a shorter style to get used to a change before the ultimate hair loss was thrust upon me. I did. Then, when I was in the hospital and I knew total hair loss was imminent, a nurse offered to shave it off before it completely fell out. I took her up on it.

Some women and men go to hair salons and ask to be seen in a private room to have their hair shaved off. Others hold a party and have their friends and loved ones participate in shaving off their hair.

When my hair started to grow back, some asked how long it too. It took four months for a fuzz to appear. It took longer for my hair to grow than usual. As, like for many, my hair grew in curly. For some, their hair color also changes.

*Losing my hair was horrible for me personally — actually harder than the diagnosis of leukemia. –LL*

*I worried about losing my hair. I didn't want people at work to know what I was going through, and being a man, I couldn't wear a wig. –MS*

*Months ago, when I thought about losing my hair, I was distressed, as a bald head often serves as evidence of cancer treatment. I thought I might be that one in a million who doesn't lose their hair from these specific drugs, but the truth was revealed as long hairs decorated my pillow. While my hair is slow-growing and patchy, I've come to appreciate my bald head. It reminds me of the healing that still needs to take place. –CS*

*I was so angry about losing my hair. Then it returned snow white, not gray! –KM*

## Cindy’s Journey *Wig, Hat, or Bald?*

Dealing with a bald head is new territory for me. YouTube videos on how to tie colorful scarves into a stylish look end up being less than stylish on me. Winter hats are itchy. My husband’s sports team’s hats don’t match my outfits, which for some reason matters to me. So I order ten, yes ten, Vineyard Vines™ baseball-style hats in different colors. The fabric is comfortable, and the shape of the women’s hats fit nicely around my shiny scalp. If you aren’t familiar with Vineyard Vines, their smiling whale logo is found on their apparel. The “whale” hats are my go-to when I don’t want to bother with my wig.

But now, I stand in front of my open suitcase wondering what to pack for a trip to New York City to see our son and his family and to attend the musical *Dear Evan Hansen* on Sunday. My Vineyard Vines hats will be just fine when seeing our son, but after the play, we’ll see a group of our friends for the ride back to Maryland.

A debate swirls in my head.

I should wear my wig. *Ugh, it’s going to be hot, and the wig makes my scalp sweaty and itchy.* But it looks like your real hair. *If I wear or take my wig up to NYC, I must pack the Styrofoam head it sits on. It would be so much easier to go wigless.* I don’t want to shock my friends. They haven’t seen me since I lost my hair. *They won’t care.*

The volleying back and forth continues until comfort and ease finally win out. I am going without hair, scarves, hats, and wigs. I tuck my vulnerability down and call upon my courage.

Sitting in the theater, knowing I will soon see my friends, my anxiety begins to rise. Just as my self-consciousness is about to take a firmer grip, I am thrust into riveting scenes unfolding on stage. The play portrays adolescent angst and more, yet an undertone is the desire to be seen. The irony is not lost on me. Well, be seen, seen without hair.

As we walk to meet our friends, I realize for the casual passer-by, seeing someone without hair is just that: someone without hair. But for me, being bald symbolizes the journey that is taking me on twists and turns, worries and fears, illness and pain. The outward symbol of hair loss is proof that an unwanted guest has struck my body. Hair or no hair, wig, hat, or scarf shows the world, and more importantly shows me, that my life has changed.

Oh, by the way, the play was fantastic.

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## Fatigue and Sleep

*A bone weariness consumes me. It is definitely one of the most severe and long-lasting of all side effects. –CS*

According to Sleep Advisor.org, in January 2020, falling asleep should take between 10-15 minutes. In the U.S., 50 to 70 million people suffer from one or several sleep disorders; 30% of U.S. adults suffer from insomnia, and 10% from chronic insomnia.[2]

Sleep difficulties and cardiovascular disease (CVD) illustrate the relationship between sleep and health. Poor sleep quality contributes to CVD, and CVD may interrupt sleep.[3]

The National Cancer Institute reports that as many as half the patients with cancer have problems sleeping due to insomnia and an abnormal sleep-wake cycle.[4]

Dr. Merrill Mitler, a sleep expert and neuroscientist at the National Institutes of Health (NIH), explains that sleep serves all aspects of our body in one way or another, including energy, intellectual function, alertness, and mood.[5]

Sleep promotes clear thinking, quick reflexes, and strong focus. When we sleep, the brain cortex interprets and organizes the information we gather when we are awake. Not getting enough sleep leads to difficulty making decisions and solving problems because our brains haven't had the time during sleep to organize all that we experience.

Dr. Michael Twery, a sleep expert at NIH, comments that a lack of sleep "… affects growth and stress hormones, our immune system, appetite, breathing, blood pressure and cardiovascular health."[6] During sleep, our bodies release hormones that help repair cells — a process of paramount importance during medical recovery.

Similarly, sleep is essential to our memory. During sleep, our brains take what we experience during the day and route it to a different part of the brain, which stores it. This long-term memory bank allows us to recall the information and use it later. If your mother told you that you needed a good sleep for learning, she was right!

*There were constant physiological issues: fatigue, nausea, body aches. –JN*

*The hardest part of my experience was having bad days when my energy level wasn't high enough to function. That was not me before; now I must go as my body lets me go. –SJ*

### Cindy's Journey *I'm Not a Napper*

I feel for those who have chronic sleep issues. It is so frustrating to lie in bed tossing and turning, counting sheep, wearing a sleep mask, or listening to calming music only to still be awake.

For me, falling asleep is easy. Okay, okay, to be completely transparent, I take a small dose of prescribed Ambien every night. Yet, no matter how long I sleep, I combat a level of fatigue during the day. I haven't found a good word or phrase for this type of tiredness. Fatigue and tired just don't capture the depths of what I feel. Bone weary is the best I can come up with. The fatigue is all-encompassing; it consumes me. It zaps my physical and mental energy.

Those who love me tell me I should nap. I am not a napper by nature. I like to do and move. But, by 1:00, I feel like a plug has been pulled and all my energy leaves me. And so, I take to my bed.

Lying on my bed under a comfy quilt, I flick on HGTV to watch a family's search for a larger home for their growing family or marvel over the Property Brothers' inspiration to makeover an old home. But, just as the families are choosing paint colors and kitchen flooring, I turn it off. I just don't have enough energy to finish the house renovations with them. And I close my eyes, turn on my meditation app, and this anti-napper sinks into sleep.

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## Eating

*I used to crave pasta. A bowl of plain noodles was as good to me as a gourmet meal. Somewhere along the way, I lost my taste for pasta. –CS*

While "feed a cold, starve a fever" might not be true, appetite changes often occur during this time. Some of us experience an increase in appetite, while others note a decrease, or a change in food preferences. Steroids are known to affect metabolism and how the body deposits fat. This can cause an increase in appetite, sometimes leading to weight gain.

Appetite loss is common among those who have undergone surgeries and in patients with cancer. According to Cancer Treatment Centers of America,[7] some cancers, particularly those of the gastrointestinal tract (like stomach and pancreatic cancers, as well as ovarian and lung cancer), often decrease appetite. Many anti-cancer drugs and treatments are also linked to a loss of appetite, particularly chemotherapies known to produce nausea and gastrointestinal reactions.

### Cindy's Journey *One Bite at a Time*

I have put my all into eradicating this disease and being healthy. I follow my doctor's advice, walk regularly, take supplements, get acupuncture, use other alternative health interventions, work with a physical therapist, and rest more than I ever have in my life. The one area that could be better is my eating. I crave avocadoes, berries, and, wait for it, fried chicken! The first two are good choices, but fried chicken? I don't know why fried chicken made the list, but there is something in it that I yearn for. Prior to this craving, I must say I had fried chicken fewer than a dozen times in my life. Now, I can describe the virtues of various fried chicken venues. Even with an increase in my consumption of berries and avocadoes, I knew I could step up my "food game," so when a friend told me about an all-day conference about eating well and the benefits to one's health, I signed up.

The first presenter was riveting, extolling the benefits of a plant-based diet. For those of you who may not know, this is code for a vegan diet. The information made sense, and I was ready to sign on the dotted line. Then, a chef prepared four recipes for us to taste at lunch. He chose easy-to-make recipes, and I found myself thinking, "I could do this." Lunchtime rolled around, and in front of each of us were a couple of spoonfuls of the vegan version of macaroni and cheese. Now, if there is one thing I know, it is macaroni and cheese. I LOVE pasta, and as for melted cheese? What's not to like? I couldn't wait to dive in and taste this healthy version made without dairy products. I took a taste and… you got it: nothing like any macaroni and cheese I've ever had. Not even close! The "cheese," made from cauliflower and other ingredients, missed the mark. If the taste passed muster, I would have left the conference and gone out to buy every needed ingredient to convert my pantry to a vegan-friendly one. Steak, ice cream, and eggs be gone.

My resolve was dampened, but the intention of changing my eating habits was not completely lost, so I moved to the edge of my seat to hear the next speaker, who was an authority on the importance of specific foods to ward off cancer. The speaker's authoritative manner and easy-to-add food choices further engaged me. Eat more green veggies. I can do that, check. Eat beans…well, okay. Eat seeds…got it. Eat onions, garlic, and mushrooms. Hm-m, okay, I can add those to recipes. Berries are necessary as they contain cancer-fighting agents. Well, I have that one mastered. I leaned back with some ease; I could definitely step up my nutrition with these items.

As the conference went on, I hit my inevitable wall of fatigue. I packed up my folder and handouts, scooted past those in my row, and left the room to head home for a rest. As I drove home, my car turned into a shopping center. I went into the shop and made a quick purchase. Back in my car, I continued home as I sunk my teeth into the shortbread cookie. A wave of guilt wafted over me. There wasn't a bean, berry, green veggie, onion, or mushroom to be found in the buttery dough… but, boy, was it good.

## Nausea, Diarrhea, and Constipation

Our bodies are complex systems. Just like falling bowling pins, one event can cause a chain reaction. Chemotherapy, anesthesia, medication, and stress can affect the gastrointestinal (GI) system, causing nausea, diarrhea, and/or constipation.

Chemotherapy often produces GI reactions. Chemo drugs can change how the body breaks down food, disrupting the GI system. Some chemo drugs irritate the lining of the throat, stomach, and/or intestines, making it difficult to eat a regular diet further stressing the GI system. And as many of us know, it can cause us to vomit.

GI reactions are not restricted to chemo. Medications, particularly pain medications like opioids, can negatively affect the GI system. Anesthesia slows down the movement and motility of the GI system. Our medical situations might cause us to be more still and sedentary, and this lack of body movement can further slow GI functions. When the GI system works more slowly, food and waste aren't processed as usual, resulting in constipation.

Stress compounds gastrointestinal challenges. The stomach and intestines have more nerve cells than the entire spinal cord. The nerve cells in the gastrointestinal system communicate with the brain; this is referred to as the gut-brain connection. We have common sayings that illustrate this gut-brain link. We "feel butterflies" in our stomach when we are anxious. A difficult situation can be referred to as "gut wrenching." A challenging situation sparks us to remark that we "can't stomach" it.

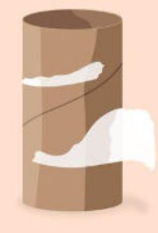
For more information on the stress-body connection, stress expert Robert Sapolsky, expounds on this connection in his book, Why Zebras Don't Get Ulcers. He does so in an engaging and sometimes humorous way.[8]

## Cindy's Journey *Shit Happens*

Today is a beautiful spring day with the temperature hovering around 66°. Trees are beginning to bud, the sky is a brilliant blue, and the sun is starting to warm the earth. I put on my workout pants, headphones, sunglasses, and ventured out to walk to the shopping center a little more than a mile away. I feel the sun warming my face as the music wafts through my headphones, my arms swinging to the beat. This is the first day I have been able to "exercise" in months. I drink it all in. I am happy.

Phil Collins sings "Against all Odds" through my headphones and I muse on the words, letting them empower me to handle this disease. Such conviction is abruptly interrupted about three-quarters on the way: my intestines start to revolt. I need to find a bathroom. This isn't my usual experience. This is different. This is uncontrollable. This is an emergency.

A high school looms to the left. There is no way I can quickly explain that I need to use their bathroom. In this day and age, they don't let random folks in through the door and I don't have an ID to show them. I was just out for a walk. I'm not prepared to be scrutinized by high school security. I hurry by the school, knowing the shopping center is around the corner. "I can make it" becomes my mantra. McDonald's is my goal. I will be able to scoot in the door without needing to greet someone or show an ID. I pray I can get into the bathroom quickly. My steps hasten. I try to distract my mind and body with the songs that play through my headphones. No luck. BOOM. It happens. "Oh, shit."



I get to the ladies' room and yes, as humiliating as it is, the diarrhea side effect of the chemo the medical team talked about has hit. It has hit all over me. I untie my shoes, take off my workout pants, and remove my soiled underwear to find there is one square of toilet paper in the stall. Seriously? One square? My frustration mounts. I look behind me to see if a roll of paper sits somewhere else. Nope. Well, this won't do. Naked from waist down in a stall with no toilet paper, I wrap my warm-up jacket around my waist and quickly dash into the other stall. Phew, toilet paper. I continue to fill the toilet. It comes furiously. Flush, flush, and flush again. This cycle repeats. Thank goodness, no one has come into the bathroom. It's noon, which is typically a busy time, but I have the place to myself. Flush, flush, and flush again.

I throw my underpants into the trashcan and tie up the plastic bag so my secret stays hidden. I clean up the best I can but tears well in my eyes and frustration washes over me. I didn't expect this. I didn't want this. My mind whines with self-pity as I lament that I can't even take a walk with predictability. For the first time, I feel sorry for myself.

Leaving the stall and bathroom, I realize walking back home is too risky. What should I do? I am not one who easily asks for help, although people have sincerely offered any assistance they can give. I call a friend who lives close by. She answers, but she and her husband are hiking at a park. I call another friend. She will check out of a store, come right over to pick me up, and cart me home. She arrives with compassion. She understands. She doesn't recoil in disgust at my tale.

She swings her car into my driveway and a wash of relief comes over me. Climbing up the steps to my room, feeling achy and fatigued as my intestines let me know they are still there, I am grateful to be home. I shower and then sink into my bed for a bit of a rest, looking out the window at the sun that continues to shine, promising hope and bright days. But today, shit happens.

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## A Challenged Immune System

*During my chemo treatment, I was careful about placing myself in large groups. I did not want to unnecessarily fatigue myself or overexpose myself to germs. –MM*

Our immune systems help us stay healthy and fight infections. When our bodies are battling a disease, injury, or stress, keeping our immune system healthy becomes more of a challenge. Our awareness is piqued, as we understand that microscopic germs float through the air. This can thrust even the steadiest of us into a rather obsessive-compulsive state. Even before COVID, we become avid hand washers and learn how to push elevator buttons with elbows and open doors with a hip or forearm. We aren't afraid to change seats in the doctor's office when someone lets out a sneeze and a cough. We don't want a casual encounter to interrupt our treatment or healing.

*My boys were in middle school and were excessive germ carriers, so I was limited on seeing them. When they would visit, even though I was in a special isolation room, they were required to wear masks, gowns, gloves and even shoe* *booties. My husband and I would do the same, so they didn't feel bad. My diagnosis and losing my hair cannot compare to the possibility of missing out on their lives. I would say this was the hardest part. The fact that at almost 12 years old, they had to deal with some very serious matters. –LL*

## Pain

There are different types of pain. Pain can have a positive function warning us if something isn't right. Feeling pain when lifting a heavy box lets us know that we  overstressed a part of our body. If we ignore the warning and continue to lift boxes, an injury can be worse than it needed to be. Paying attention to our body is essential in getting assistance. Stabbing pain can be a warning of a heart attack, appendicitis, and more.

*When my mom was first diagnosed with Stage 4 lung cancer, she didn't have any pain. As the disease progressed, she had more pain. It was horrible to see. There was a day she was having a terrible time, in a lot of pain, and crying out when the aides came to help her. I lost it completely when I got home. –AR*

Another category of pain comes from the illness, injury, or surgery itself. Having the flu makes us so miserable that the discomfort pushes us to rest and take care of ourselves. Rest and care help ward off complications. I've heard many people say they were shocked when they were diagnosed with cancer because they didn't have any pain. Not all cancers create pain. Bone and advanced cancers can produce pain. Tumors pressing on a part of the brain or body can result in pain. The pain from surgery, bone breaks, concussions, and more remind us that our body has been assaulted and needs care.

*I get headaches now. I'm not sure if they are from medication, fatigue, or stress, but the pain prevents me from functioning. –CS*

*Getting off the morphine was a journey into adjusting to the pain associated with the surgery. –GW*

Chronic pain and diseases are the worst. I don't think people with such things get the support they deserve. It's easier to respond to someone after a heart attack, cancer diagnosis, etc. Others, including medical personnel, typically don't understand what it means to have chronic pain. What people see on the outside doesn't represent what is going on inside.

Dr. Sheetal DeCaria, an anesthesiologist whose work is dedicated to pain management, presents a Tedx talk entitled The bias behind your undiagnosed chronic pain
https://www.ted.com/talks/sheetal_decaria_the_bias_behind_your_undiagnos

ed_chronic_pain?utm_source=tedcomshare&utm_medium=email&utm_campaign=tedspread

Dr. DeCaria shares the implicit biases about how women, children, and minorities are misunderstood and underserved in the treatment of pain. Being their own advocate becomes essential due to these biases. It's hard to be your own advocate when you are in pain. Mustering up that energy is furthering depleting. Nurse practitioner, Linda Eld, who oversees treatment in urgent care centers, shares that urgent care centers have limited long term resolution of patients' pain. The result is patients receive referrals to other medical care providers which can often seem to patients that they are being brushed off…again.

*Due to osteoarthritis, my surgeries, and the impact of the disorder my medical charts read like a case study. It's hard. I am often in pain. It's difficult for others to understand. Recently someone I know had a torn meniscus. She apologized that she never realized the degree of pain I was/am in, since she had never experienced anything like it before. –LE*

*From the car accident, I have a metal plate in my head that causes sinus congestion and magnifies pain. I also have allergies. The combination of allergies, sinus congestion, and the metal plate often leaves me in pain. –CK*

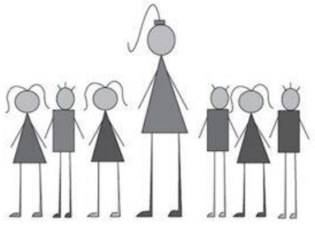
## Unexpected Changes

Even with the best care, things happen that we don't anticipate. Unexpected changes can run the gamut. Some have long-lasting results.

*The side effect no one told me about was it brought on my menopause at a faster rate. So then I was dealing with night sweats, personal summers (aka hot flashes), physical body changes, etc. –RG*

*I had a severe chemical imbalance in my brain following surgery. I am under the treatment of a psychiatrist who prescribes anti-depressants, anti-anxiety and mood stabilizer drugs. I will be on these my whole life. –JZ*

## Cindy's Journey *Taller Than a Sixth Grader*



I used to be tall. As a fourth grader, hitting my growth spurt on the early side led me to inch past my sister, Debbie, in sixth grade.

Referring to me as her “big little sister” to her friends brought smiles to their faces and confusion to mine. Being nine years old and focused on acting out WWII battles and playing in the dirt with the boys across the street, I was unaware of how my body was changing.

On a beautiful spring day, Mrs. Clark, my engaging fourth-grade teacher, walked me down to the cafeteria. My mother had asked that I join my sister’s class for a movie. Wow, did I hit the elementary school jackpot or what? It was unlike my mom to let me miss class, but today must be my lucky day.

Entering the cafeteria rows of chairs replaced the usual lunch tables, I noticed the room filled only with girls in the sixth grade. Perplexed, but eager to reap the reward of getting out of class, I followed Mrs. Clark as she walked me over to sit with my sister’s class. Approaching them, I heard her friends ask my sister, “Why is she here? This is for sixth graders.” Debbie shrugged her shoulders as I took the seat at the end of the row.

The school nurse stood in front of the group, asked for quiet, and announced we weren’t to discuss the movie we were about to see with anyone other than our mothers. I thought that was odd. Then the lights dimmed, and in vivid black and white, images of a girl’s body and drawings of the reproductive system flashed on the screen. The movie’s narrator stated how her body and “yours” would change over the next few years. “Oh no, this isn’t good,” my mind screamed. I sent up a universal plea to take me away. I would do extra math, spelling, reading — anything to get out of here. But there I was, on a metal chair among a sea of sixth grade girls. Closing my eyes and ears, I melted into my seat, sliding away from the messages on the screen.

At the end of the movie, the lights flicked back on as the nurse directed us to walk back to class when our teacher’s name was called. Was Mrs. Clark going to come back for me? Would they announce Mrs. Clark’s name as if she were a sixth-grade teacher so I could leave? As the last class was called back to their classroom, I knew Mrs. Clark was still in our classroom, discussing the solar system or something else interesting with the rest of my class that I was missing because of this horror film. Still in a state of shock, I got up as the last class was called and stood at the end of the line. Walking in single file down the hall, I took a left, leaving them in my fourth-grade dust, bolting back to the safety of Mrs. Clark and my less developed, more innocent peers.

When I got home, I was going to follow the nurse’s directive and talk to my mom. I wasn’t going to talk about reproduction, menses, or breasts, but she had some explaining to do as to why she sent me to the sixth-grade horror show. Upon my tearful questioning, my logical mother, an OB delivery nurse, calmly explained that since I was growing more quickly than many of my friends, she wanted me to have the information so I wouldn’t be shocked when changes took place. Well, Mom, shock me now or shock me later; I am shocked.

As more typical daily events replaced the distress of the movie, my body continued to grow and change, and I started my period two short months after the movie, proving once again my mother is always right. Dismayed and not ready to embrace the changes, I kept it a secret from my sisters and friends for years. My growth also continued, reaching 5’7” in sixth grade and over the next few years two more inches would be added. I liked being tall. It was part of my identity, assisted my basketball success, and was simply me. But I am not tall anymore. It’s quite hard to get used to.

At one of my many doctor visits, a nurse had me step up to be measured. “Five six,” she announced. “5’6”? That’s not right! I’m 5’9”!” “It says 5’6”, so that’s what it is,” she proclaimed. Through the fracturing of my vertebra, radiation, age, and who knows what else, I am now 5’6” — maybe 5’7” on a good day. To many, this may not seem like a big deal, but when I stand next to my grown children, I notice the difference. When I try to reach the top cabinet shelf, I notice the difference. When my pants dip over the top of my shoes, I notice the difference. This is one of the many changes that this disease has created. After all, I used to be taller than a sixth grader.

* * *

My husband and I sit side by side and work on crossword puzzles. You might think it is a collaborative effort, but we turn it into a competition. He prints out two copies of the same puzzle, and with pencils in hand, we work separately, racing against each other to see who is first to accurately complete the puzzle. I must admit, he usually finishes sooner. The other night, a clue appeared asking for an “effect of surgery.” At first, I couldn’t think of what the answer might be, but the four empty boxes tipped me off. Scar. Yup, a scar is an effect of surgery.

Scars become constant reminders of childhood injuries, surgeries, and more. I have a round scar near my ankle that happened when I was about eleven years old and ran into the corner of the bed frame. Without the scar, I wouldn’t even remember this incident. The scar reminds me of a moment that occurred so long ago.

Visible scars can alert others to a situation we have encountered, but invisible scars sit within us, and people we encounter don’t know they are there. These invisible scars have an impact on our lives.

### **Cindy's Journey** *What Is Her Name?*

Today, at a store, I saw someone I knew. I started to move toward her to say hello, only to realize I couldn't think of her name. I quickly scooted behind a sales rack to avoid her. But wouldn't you know? She began to move toward where I was standing (hiding). Looking at my list to avoid eye contact, I mentally scrolled through what I knew about her to try to unlock her name.

As I struggled to find her name, a remnant of my memory flickered. Wait a minute. This should be easy, as her name is the same as a famous actress from the past. Flipping through a mental list of female actors, nothing useful came forth. Not to be outdone by my now-lousy memory, I grab my phone and input the name of her company, hoping to land on a useful clue. Nada. Nothing. Nil. So I do what any self-respecting person does? I go down the pasta aisle.

On my way home, I focus on the road, allowing my brain to relax, and her name pops into my mind. It feels so good to have the recall. For the rest of the way home, I smile as Joan Collins is recovered from my memory bank.

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[1] https://www.cancertodaymag.org/Pages/cancer-talk/What-Is-Chemo-Brain.aspx
[2] https://www.sleepadvisor.org/sleep-statistics/
[3] Jeannette Y. Wick, RPh, MBA. "Sleep disorders and heart disease: a reciprocal relationship," Pharmacy Times, December 10, 2014).
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[6] https://newsinhealth.nih.gov/2013/04/benefits-slumber
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## 11-Your Emotions During Treatment

As if the physical changes and conditions aren't enough to cope with, medical trauma has a significant impact on our emotions. Healthcare providers may have facts and statistics to help us understand physical challenges, but they are less prepared to help us cope with the emotional swings that come with such experiences. Understanding typical reactions to some commonly felt emotions can help us move forward.

## Unwanted Dependence and Vulnerability

*It is so frustrating. I leave messages for my doctor. No call comes. I wait weeks for a needed test to tell me the next steps. Each minute, each hour, each day feels like an eternity. All this waiting. –LH*

As we go through surgeries, treatment, rehab, and more, many of us find we are launched onto an unfamiliar path. Despite the uncertainty, we try to gain balance, but we feel it is a bit like the playground seesaw. Sometimes we are lifted toward the sky, and other times, we are precipitously dropped to the ground. Finding the needed balance is difficult.

As part of human evolution, we strive for independence. We can see the quest for independence throughout development. Two-year-old children push the limits and reject adult direction as they embrace their ability to walk, talk, and assert their desires. The quest surfaces more pronounced during the teenage years when adolescents recoil from having to ask for permission, request help, or respond to their parents' inquiries about where they are going. Treasuring self-sufficiency in our adult years is considered a sign of success. Independence feels good. Yet the vulnerability and inherent dependence on professionals and others during this time can throw off the balance of what we've worked so hard to achieve.

An even higher level of evolution is interdependency. Interdependence is the balance and rhythm of the seesaw. Interdependence recognizes that the extremes of dependence and independence miss the mark. Interdependence requires us to appreciate the value of working with others, engaging in give and take, and recognizing our limitations and needs. Interdependence increases our chances of survival and interpersonal growth. It's okay to be lifted.

*Waiting for calls and results was the hardest part. –MR*

*It was so hard to have a young child during this time of the unknown. Without me, she would be more vulnerable. –RGW*

*I suppose the most difficult feeling was one of vulnerability and not being in control. –MB*

## Worry, Anxiety, and Fear

Many use anxiety, worry, and fear interchangeably. They all represent states of discomfort that can be experienced when we feel vulnerable, threatened, or uncertain. Anxiety, worry, and fear are emotional reactions with some similarities, yet they differ.

- Worry tends to create mild emotional distress

- Anxiety creates more persistent distress
- Fear is the sense of immediate danger

### Worry

*I passed off the treatments as an "inconvenience," but inside I was worried that I could go through all of this and have no change in diagnosis. –DP*

Worry is a thought or an idea that can take different forms. We might ruminate about whether we are making the right treatment decision, whether or not our medical team is the best, what the outcome will be, or how our families will cope through this time.

Worry can move us to make decisions and problem-solve. If we are concerned about a treatment decision, we might contact others and ask their opinions, do research, and/or talk to experts. Worrying about the outcome can motivate us to seek complementary interventions, such as acupuncture, changing our diet, engaging in exercise, and more. Similarly, when we worry about how our family is coping, we can encourage them to identify friends they can talk to, ask others to check on them and have them talk to us about their concerns.

*The ringing of the phone pierces the unrelenting agony of my pain. Suppressing what I am feeling in my voice, I answer in my best upbeat tone. I want to shield the caller from my pain. My intention is not entirely altruistic. Keeping much of my pain hidden shields me from their worry. –CS*

*I used to cry during radiation treatments. I had a skin reaction to the tape they used and although I repeatedly told them about it, they ignored my complaints. This made me worry even more that they weren't doing their job correctly. I didn't trust them. –RG*

*I get distracted by worries.  As I get my fifth blood transfusion, I think, what if something goes wrong?  My mind takes me on that awful journey where nothing ends well. As thoughts spin around, I grab onto a fleeting thought, 'Just be normal.' I then visualize myself being healthy and fully engaged in life and all is okay in my world.  When the winds of worry bend my sails, you'll see me uttering, 'Just be normal' and my ship becomes right again. –CS*

### Cindy's Journey *I Hate Worry*

Worry eats at my resolve and competitive nature to win this battle. Worry shifts me into the unknown. Worry takes me into the future of how my kids will handle the impact of this disease and my possible early death. Worry makes me sad, wondering if my grandchildren will remember me and if I will be around to see the grandchildren yet to come.

I hate worry. Worry makes me cry.

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## Anxiety

> *I'm not sure I could live life with the levels of anxiety that I was experiencing during treatment. While the treatment of leukemia was difficult, dealing with debilitating anxiety was exponentially worse. –GM*

Anxiety is characterized by thoughts paired with visual images. Thoughts and visuals are linked together to be stored in our minds. Engaging different parts of the brain creates a more powerful experience. Reading a book and picturing the scenes trigger the language and visual parts of the brain, which make the book more memorable. Movies create additional memory recall because they have words, pictures, movement, and sound — a brain feast! Because anxiety involves thoughts and images, it tends to have more power than worry and therefore is harder to control. Anxiety causes more distress.

Over the years, I have worked with many children and adults with anxiety. I thought I understood what it is like to have high levels of anxiety: heart palpitations, persistent thoughts, obsessive thinking, difficulty concentrating, and high startle responses that even sleep doesn't quell. It wasn't until I reacted to a medication that I truly learned what it is like to have uncontrollable levels of anxiety. During that time, I couldn't move beyond the pain and reactions of the anxiety. I couldn't control my thoughts and feelings. I felt at a loss as to what to do. I tried everything I could think of listening to music, walking, meditating, breathing, talking, and repeating positive statements, but nothing helped. It wasn't until my physician determined I was having an allergic reaction to the medication and took me off of it. "It's rare," he said, "but it can happen." Well, happen it did! I have a newfound level of compassion and understanding for those who suffer from chronic high levels of anxiety.

> *I felt very alone even though I met other people in the waiting room who were also going through radiation. We went from one waiting room to another. In the second one, you changed into the robe and waited alone. They had magazines to read, which were all about cancer. It wasn't something I wanted to look at as I was about to enter my radiation treatment. I couldn't believe that was the only reading material they had. It would have been good to have someone there to talk to about your fears and anxiety.*
> *–RG*

> *My anxiety is so high. [Thoughts] that he really could die from the surgery as it was so long, what would he look like after it, will it come back, will this kill him, how much longer will he live… so many unknown answers. –LH*

*I was anxious about the treatment and, at the same time, hated that people felt sorry for me.–DP*

## Fear

> *I felt fear associated with the unknown. Would radiation be successful? Would it return? Would it spread? Am I doing the right treatment? Is it enough? You put your life, your faith, and your trust in people you don't know. It's a very frightening experience. –RG*

Fear is essential to human survival. Without fear, our ancestors would have all been eaten by the mountain lion!

Fear is a normal and protective response to danger, and certain fears are developmentally appropriate. Around the age of two, children's brains can imagine and think about things that aren't there. This is why you see a surge in creative play at this time. They can take cars and have them talk. Sitting at a computer, they pretend to type. Dolls need to be fed and changed. This is truly a time of wonder for those blessed to watch this emerging growth. While imagination and creativity are hallmarks of brain development, the brain can also imagine situations that create fear of the unknown: monsters under the bed, whether lightning will strike the house during a storm, and more. When the fear of the dark kicks in, nightlights are switched on, portable flashlights are tucked under the covers, and a snuggly toy becomes a source of comfort. These supports help soothe the brain until the fear passes.

In situations that aren't usual (e.g., violence, hunger, abuse, crisis), fear remains high. At these times, fear takes on features of worry and anxiety. When feeling fear, worries, anxiety, obsessive thoughts, "what ifs" and the physical sensations of anxiety combine to create a high level of distress. Once the situation that evokes fear is lessened or removed (e.g., you heal, the crisis is over), the fear should diminish.

> *I was diagnosed with multiple sclerosis and eight months later with breast cancer. I was scared and terrified. I made sure all my affairs were in order. I wrote a letter to my husband, my daughter, and my sister to be opened upon my death. –SR*

> *I was scared out of my mind, but I knew what I had to do. I was in the hospital for six weeks in a specialized isolation room. I received 12 blood transfusions, plasma transfusions, platelets, and chemo. The fear of not being around my twelve-year-old sons kept me on the edge of a cliff. –LL*

> *I had a craniotomy. I was asleep for the five-hour operation. I was so frightened that I had them give me anesthesia before going to the OR. –JZ*

*[When preparing for brain surgery] I was afraid if things did not go well, I would be left alive with a severe brain injury like my Mom who was in a coma with brain trauma for months. –BK*

## Sorrow, Loss, and More

*I was eight years old when I was diagnosed with skin cancer. I was so confused. My parents tried to explain what was going to happen, but I just wanted to do gymnastics and play. –AB*

Worry, anxiety, and fear are heightened responses. They can make us feel like everything is revved up too much as if we are walking on unstable ground. Sorrow, sadness, loss, and the like lead to intense feelings pulling us downward. Just like anxiety, these feelings interrupt our regular thinking style and ability to function.

Intense emotions of sorrow, sadness, and loss can override our sense of hope. Hope is an essential element in coping. It can be a Herculean task to build a solid life on days that lack hope. We cling to the notion that life will get better because, without hope, dark days become darker; sadness becomes deeper; beliefs become shattered; and giving up takes over.

*The initial feeling of loneliness was sometimes overwhelming. –NA*

*Some of the meds had a side effect leading me to have a shorter fuse when dealing with family. –GM*

*PTSD has caused me to react in untypical ways. When I saw my teacher wearing a particular type of high-heeled shoes, I collapsed into a fit of hysterics. I was triggered because the social worker from Child Protective Services wore shoes like that when she was questioning me about the sexual abuse I experienced. –BR*

*I was so frustrated and angry that I couldn't eat, sleep, speak, see well or take care of myself. I felt depressed and alone. –CK*

*To the casual observer, I look fine, but right below the surface the tears are ready to burst through. It happens. My heart opens a crack and here they come; not just a tear or a gentle sob, but a torrent of tears linked to sadness, worry, and memories. I quickly put a lid on it because I don't know when the tears will end. I don't have time to give into the flood. I have to be normal. I have doctors' appointments, visitors, work, and healing to do. –CS*

*I was so debilitated physically that my emotional well-being depended on being able to get through the day. It was difficult to think beyond the treatment. I simply couldn't imagine a day when life would return to "normal." I was mired in* *my sorrow and couldn't feel joy when someone close to me had good fortune. The "what ifs" took over my mind and I had difficulty getting beyond that mindset. –JN*

*My daughter's mental health crisis and her various treatments affect my mood. I feel extreme sadness. I feel guilty. I try to keep a positive outlook, but it is hard because I don't have any control over outcomes. –KW*

## Keeping Emotions at Bay

*Being interactive at work was therapeutic for me. It kept my mind off all the possible risks and side effects. –BK*

When in a crisis, we strive to "look okay," as it can help us avoid feeling swallowed up by the challenges. While we might be able to dupe those around us, we know the truth as our emotions and thoughts knock within. Our jobs, families, and pleasures don't wait for us to get stronger, feel better, or cope. Life marches on, whether we are ready or not.

*I wait as the salesperson ambles down the aisle. There's no hustle. No sense of urgency. Doesn't she know I could be dying? –CS*

*It is so difficult to try not to plan, not knowing what will happen to my health. –RZ*

*It was so hard to be isolated from the regular world. –MF*

*There were some days before the second surgery when I did a lot of work on myself and realized I could only be around people who could support me in a healthy way. I worked very hard on letting go of the result of the surgery. I remember the morning of my surgery, the nurse told me she had never seen such normal blood pressure. I was in a really good place. –GW*

The emotions of these times can feel like hurricane season in the Atlantic Ocean. The emotional waves are choppy, rough, unyielding, and causing destruction in their wake; yet for some, there are moments of growth, clarity, and grace.

Many of the adults I work with in therapy who were undergoing significant crises have moments of rapid growth and self-awareness. Crises will do that to you. A crisis can bring us to our knees and draw out the deepest of our fears and emotions, while at the same time bringing us to a swell of understanding we might not have otherwise reached.

One woman I worked with had a series of miscarriages. Each one was a deeply felt loss. Her grief was deepened when others would make comments such as, "It's better this way." "Something must have been wrong with the baby." After years of losses, she decided to give up on becoming pregnant. A different set of losses set in.

One day, she glided into my office and announced she was unexpectedly pregnant. As the weeks passed, her understandable worry took hold. She and her husband decided not to tell anyone she was pregnant, even their families, to avoid hearing comments that hurt.

On one particular Tuesday, she wasn't in the waiting room when I went out to greet her. It was unlike her to be late. Five minutes into her appointment time, my phone rang. It was her husband. She was in the hospital. The night before, she had given birth to a baby boy the size of a soda can.

With her son in the university's NICU, she resumed her appointments with me. I had never seen her look better. She shared that even though her son had multiple challenges and would likely have limited sight and developmental delays, she was happy. She was happy to be a mom, no matter what. This crisis gave her calmness despite what was happening and bound to occur. It made her realize that no matter what, she would be there for him, and even though she was sad that he would face hurdles in his life, her life was better for having him. Crisis can do that: it can help us see the gifts we have and define what is important.

*Although diagnosed with acute lymphocytic leukemia (ALL) and bladder cancer, I was fairly calm. I focused on what I was grateful for and the life I had lived. I thought that if I licked this disease, any additional years would be a bonus. –GM*

*Despite having multiple sclerosis and breast cancer, I looked at the future head-on. I made the decision I wanted to live and just went from there. I had people I loved and art to create that was trying to get out of my MS brain. –SR*

*I always felt positive. I just knew I would pull through both bouts of different cancers. –LT*

*I don't know if I ever thought I was going to die. I couldn't imagine that. Of course, I knew multiple myeloma can be fatal, but I just didn't go there. –NA*

## Living "Normally"

*Try to function and live as close to normal as possible. –MB*

There is nothing that feels normal about situations that disrupt our lives. Ready or not, the events propel us into an arena few are prepared for. With so much being different, we strive for normalcy in these abnormal times. Creating balance and maintaining valued parts of our lives help carry us through.

One of the most inspirational examples of living “normally” is Maggie Kudirka. Maggie was a professional ballet dancer with the Joffrey Concert Group. At the age of 23, she was diagnosed with Stage IV metastatic breast cancer, requiring various treatments, removal of both breasts, and loss of her hair. Anyone who knows dancers understands the dedication to their craft begins at an early age. Dancing is part of their souls, and Maggie is no different. *Photo: Maggie Kudirka (by Luis Pons Photography)*

Unable to continue to dance professionally due to the treatment and fatigue that accompanies this journey, Maggie became an ambassador for metastatic breast cancer. She created and hosted benefits for the Dancers Care Foundation and other organizations. She is now known as the Bald Ballerina (baldballerina.org). The beauty in her dancing and soul is evident to anyone who has seen her dance. Maggie would rather be performing, and not doing so is a loss and not “normal,” yet through it she has created a different dance. Through multiple treatments and medications, Maggie is 30 and continues to defy the odds.

*I wanted to work. It gave me a sense of purpose. –RW*

*I pretended that everything was perfect. I spent a lot of time trying to make my environment perfect to correct how miserable we all were. I tried to ignore the bag of urine that was attached to my leg for four months, and the constant smell of leaking urine. My house was clean. Clothes were washed, folded, and perfectly put away. –GW*

### **Cindy’s Journey** ***One House, Two House, White House, Blue House***

I don’t remember exactly when it happened. Maybe it was always so. But somewhere along the way, I became competitive. Not the kind of competition that needs to win every game that is played. When it comes to board games, card games, and the like, my competitive drive drops to around 40%, but when it comes to my achievements, up goes the drive. As I think about it, possessing a competitive drive has served me well. It helps propel me toward goals and sustain my effort when the steps in between are wearisome and tedious.

Before my transplant, I used my competitive drive to help strengthen my body. Sidelined from tennis, working out, and many other forms of physical activity, walking became my elixir. Setting goals gave me a sense of power when much of my life felt out of control.

I've been home for three days, and already I feel cabin fever setting in. Even if the medical constraints don't restrict me from being around people, driving, and other joys, my energy level does. I wake up with a burst of energy that is applied to the routine of getting ready in the morning, leaving me with little left. After a few short hours, I am relegated to bed for a nap.

As I awake from my snooze, sunshine filters through the bare branches of the trees. The voice from within declares, "I'm going to walk." Putting on my shoes and asking Ben to go with me, we walk up our street. I set my sights on reaching the crest of our hill. One house, two house, white house, blue house, up the slope we go. The freshness of the impending winter air invigorates me. The familiar voice within beckons, "Go farther." And so, I do. We pass the top of the hill and move toward the cul-de-sac. One house, two house, white house, blue house. As the sidewalk ends, we return home.

Walking up the steps to our door, the Fitbit tells me it was half a mile. New goal. Half a mile or more a day. My competitive self smiles as I lie down to rest again.

## 12-Pathways to Coping

> *My treatment isn't finished. I look at my diagnosis as a chronic disease that has to be managed as best as possible and with as little disruption to normal life as possible. –PG*

Coping with treatment can look different for all of us. The type of illness, surgery, or experience can affect how we manage. Yet, there are many commonalities among all.

### Finding Information

Over the years, organizations promoting education and understanding of specific diseases and situations have emerged. Now, with the proliferation of internet use, we can search out, for example, the American Heart Association, American Cancer Society, or the Multiple Sclerosis Foundation of America. On these types of sites, valuable information is given about side effects, medications, treatments, support groups, and more.

## Working with Medical Personnel

> *If confusion and distress dominate, I take more time to try to get a handle on exactly which part of what I said is having this impact and try to address that directly. The best approach is to be honest and clear, but to define what can be done and where it may take the patient.*
> *–Dr. Ted Lee, hematologist and oncologist*

> I *wanted to be a positive patient for those caring for me. I knew I had to stay strong and take my journey one day (one hour?) at a time. I wanted to be supportive of the people who were taking care of me to save my life. –GM*

> *I do my best to understand what exactly the patient wants to know about the diagnosis and what aspect of it is the most important for him or her (e.g., the details of the treatment, the prognosis of the disease in specific terms – am I going to see my child graduating, would I be able to work). –Dr. Vadim Gushchin, surgical oncologist*

Harry survived eight years following his kidney cancer diagnosis — nothing short of miraculous. The twists and turns of his medical journey took him through a range of treatments, some traditional and others experimental. Not only did he outlive the statistics and projections given for his specific situation, but he also embraced every moment he was given.

The “Harry stories” friends and family shared at his funeral illustrated his engaging personality and ability to put others at ease. Harry was one of those patients whom all the staff wanted to work with. He was appreciative, funny, respectful, and truly cared about those who cared for him. He could fight while maintaining the best of himself.

I hope to be a patient like Harry, but I know that we can’t always be. Sometimes the pain, worry, and unknown grab us by the heart and soul, yanking us into being cranky, whiny, sad, and angry.

If we hide our emotions and reactions, we don’t always get the help we need. Masking how we feel doesn’t give the medical team a chance to grasp the depths of our concerns and side effects.

While we all could use a little Harry in our behavior and intentions, it is important to share who we are and what we're going through to gain the best support and advice from our medical team.

## Be Prepared for Your Visits

1. Make a list of your questions
2. Identify the two most important questions for that visit
3. Make a copy and give your list to your practitioner
4. Have a complete list of your symptoms, concerns, recent changes, etc.
5. Have a complete list of medications, along with over-the-counter supplements you're taking, so it can be determined if there are any interactions
6. List any medication side effects
7. Ask for suggestions on how to lessen side effects
8. If you need more time, ask for another appointment or to have an extended appointment ahead of time
9. If you don't understand, ask for clarification

Professional websites (e.g., American Heart Association), physician offices, and hospitals often have a list of what to know and suggestions for appointments.

Remember what you identified as your trauma reaction tendency and utilize those suggestions.

*Courage, faith, and good doctors will get you through. Listen to your doctor, and if you don't like the doctor, find another one. –KM*

*Trust your gut feeling. If it doesn't feel right, get a second opinion. –GW*

*Be an advocate for yourself. No one takes better care of you than you do. I kicked a stupid doctor on call out of my ISOLATION room at the hospital when she came in sick. I was running a high fever and experiencing some other scary symptoms and she was going to give me an infusion of some kind. I insisted on calling my actual oncologist (in the middle of the night) and it turned out I didn't need the infusion, I needed something else. –LL*

*I requested that only doctors I trusted were allowed to check on me. –GW*

*My breast cancer was found during a mammogram. I was contacted by the radiology center. I never received a phone call or message from my gynecologist to see how I was doing. Needless to say, she never heard from me again. –MB*

*I find the most helpful approach when working with individuals experiencing a medical crisis is to independently research their history and medical information after hours. This allows me, as a provider, to better understand the various physical, emotional and psychological aspects of a patient. This ultimately enhances trust in the relationship and allows a greater ability to provide for the patient's well-being. –Dr. Leeshi Feldman, M.D. psychiatrist*

## Nurturing a Positive Mindset

*Be tough. Force yourself to believe that you will get through it. Recognize that the person you are with this illness is not who you will always be. Focus on the positive and surround yourself with positive people. –JN*

Hippocrates, considered the father of medicine, believed health is influenced by a balance of the mind, body, and environment. Over the millennia, the mind-body connection has been studied and valued, eventually emerging into our everyday language.

An idea behind the mind/body connection is that positive thoughts alter brain chemistry and not only help you feel better but reduce stress. Over time, stress can negatively affect health and interferes with the immune system, which is needed to combat simple diseases (colds) as well as more complex ones. Thus, managing stress is an important goal.

Having a positive mindset can be challenging. It is natural to feel upset, angry, sad, anxious, or detached. Creating positive messages and using them during the day can help balance out less desirable thoughts and feelings.

*I lie on the radiation table awaiting the blast of radiation to destroy the tumor. The machine emits a whir. It is the sound that the radiation is being sent. "May the force be with you" echoes through my mind. I am not a Star Wars groupie, but the well-known idiom connotes wishing one well, to be given strength and protection. Every morning as the machine whirls three times, I think "May the force be with me." –CS*

*Don't give up. Believe, even if the odds are against it, that you will survive. –MF*

*Mental outlook will have a huge impact on how you respond to therapy and recovery. Imagine yourself as a warrior vs a victim and DO BATTLE! –BK*

*Make the decision to live. –SR*

*Watch comedies, try to laugh, and eat what you can/whatever you want! –LT*

*DON'T try to read everything you can get your hands on or on the internet. There is so much out there, and everyone is different. –DH*

*Before my surgery, I recorded hours of uplifting music and played it continually while in the hospital. –GW*

### Cindy's Journey *I Like Apologies*

I like apologies. There are all different types. Some apologies acknowledge a mistake: "I'm sorry I broke your phone." Other apologies express sorrow: "I'm sorry that happened to you." Still others express regret over unintended consequences: "I'm sorry I hurt your feelings." And the master of all: "I am sorry, I was wrong." These are apologies I like. When they are delivered sincerely, they strengthen bonds of relationships and understanding. They ease the burdens of others by becoming shared experiences. They serve as a reflection of one's inner self. It takes inner strength, self-confidence, and a good soul to express an apology.

Preparing for the day, I open the drawer containing my wide selection of head coverings. The chilly winter temperatures and my self-consciousness demand that I cover my bald head; I search through the stacks of colorful fabrics, deciding which one to wear. I opt for a covering that can be a neck warmer or a headband that covers my head. With a mere twist of fabric, it serves various functions. Pulling it onto my head, covering my ears, and stuffing the excess fabric underneath my favorite Vineyard Vines™ baseball cap, I am off to my physical therapy appointment.

Climbing onto the physical therapy table, I toss my baseball cap onto the chair. The oversized headband flops to the side, revealing the top of my bald head. "I'm sorry," slips out of my mouth.

What?! I'm sorry? Why would I apologize for being bald? While explaining the sources of my back pain to the physical therapist, I carry on a private conversation in my mind, admonishing myself for apologizing for something that needs no apology. My mind digs deep to find what evokes such an apology, only to find it originates in my sense of vulnerability with my altered appearance. So I give the most important apology…to myself. "I'm sorry I said I am sorry."

## Finding Supplemental Support

*Seek support from peer groups, books, alternative therapies, and all the people in your life who are willing to give it. –MF*

Throughout this journey, as well as in life, it's important to find ways to reduce and handle the stress in life. It's important to find what works for you. What might work one day versus another can change, so having a variety of options is helpful.

When it came to treatment options, I signed up for all of them. Anything that made sense, I did. Radiation, chemo, stem cell transplant, yup, I would do it. The research showed that in cases like mine, they could help prolong and restore the quality of my life. Yet, I wasn't going to depend solely on Western medicine. I embraced other interventions; for example, acupuncture and EMDR (Eye Movement Desensitization Reprocessing) for the emotional impact of what I was going through.

To help reduce stress and increase overall well-being, many seek out meditation. When some think of meditation, they think of clearing their minds of every thought or repeating a mantra. While these are particular types of meditation, there are many forms. Having taught meditation to a wide variety of people over the years, I find guided meditation the easiest approach for many. In guided meditation, a leader uses words, progressive relaxation techniques, and/or specific images to lead the meditator through an experience. Quality meditation sites include Headspace™, Calm™, Jason Stephenson on Spotify, Oprah and Deepak Chopra's 21-Day Meditation Experience, and MeMoves™. MeMoves™ is particularly helpful for those who find moving calming.

*Guided mindfulness meditations help me handle the pain. –CK*

*I felt such anxiety. I think part of it was due to medication. There are some good psychiatrists and other physicians who should be able to help you with your anxiety. Some medications can mitigate anxiety. In certain cases, you could also benefit from therapy. –GM*

*Acupuncture was a godsend. –BK*

*The pain and PTSD that I experienced got me into yoga. My first teacher was so inspirational that I trained with her for two years and went on to teach. The pain I experienced led me in this direction. –GW*

*I am not a religious person. I am, however, spiritual. When we lost our 23-year-old son in an accident in 1999, religion pretty much left me. I have since found that meditation and Buddhist writings are a comfort to me. I don't think any of that changed during my battle. I just think that the meditation helped me keep a perspective that was healthy and manageable. –SR*

### Cindy's Journey *You're Doing Great*

My life is carved around doctor appointments. Traveling there, sitting in the waiting room, the weigh-in, blood pressure check, the blood draw, each usurping precious moments of my life. Then there is the verbal check-in:

- Trouble breathing? No
- Coughing? No
- Numbness? Some
- Nausea? Some
- Diarrhea? Yes
- Constipation? No
- Pain? Some

As the checklist routine marches on, I blurt, "I try to walk a couple of miles a day." My doctor's eyes brighten as he exclaims, "That's great!" I smile, feeling I earned the Patient of the Week Award. My inner joy fades as I want him to ask about the nonphysical impacts of treatment, but he helps me sit up and announces, "You're doing great. Really great!" I nod my head in compliance. I am doing great… until I'm not.

## Support Team

It is typical to have more than one medical professional involved in our care. For me, my internist helped me through.

There were moments and days when tears came quickly, sadness set in, and I wanted to hibernate. All else was pushed to the background when these feelings took center stage. As the upsetting days linked together, I knew I needed something more. I called my internist, described how I was feeling, and announced, "I need drugs."

She told me she often sees around the third month of treatment, patients have a surge in emotions. When first diagnosed, adrenaline is pumping. The focus is on gathering information, scheduling appointments, and creating a plan to deal with the ensuing changes and needs. Around the third month, the adrenaline abates, side effects find their place, and how life has changed becomes clearer. She prescribed Wellbutrin, which thankfully has helped. It has given me an emotional foundation again, so when the distress comes, I don't go as low. I periodically see a therapist, who is also a support. Medication and therapy lessen the frequency of the times when I am not "doing great."

Knowing how to seek out support is easier for me due to my profession, but I know many people don't know where to begin. I worry about them. Many medical teams don't want to discuss or hear about emotions. I've seen it. I start to ask a question about the unsettling feelings I am having and the PA unconsciously takes steps backward, signaling her discomfort with feelings.

I want treatment teams to ask about our emotional well-being as part of the weekly checklist. Diseases don't just affect our bodies. It would be simple. "How has this affected your emotions?" "How has your treatment impacted your daily life?" I imagine some patients sighing in relief that the question has been asked, whereas others might utter a blanket, "I'm fine," quickly scurrying to more comfortable territory. Regardless of our responses, asking such questions would affirm the normalcy of our emotions and the impact of the treatment.

When my treatment journey is said and done, I might go on a mission to enlighten and teach those in the medical profession how to better support their patient's mental and emotional health during the healing process. Who knows? I might just do it. What I do know is we are all doing great… until we're not.

## Changing Your Ways

*Learn to say YES to help. –BK*

We get set in patterns and routines because they bring us comfort. When in crisis, the patterns and routines of the past are often shattered. Medical challenges often force us to live differently.

Lisa Cohen, who seeks to empower women with multiple sclerosis in her 2005 book, Overcoming the BS of MS: A 3-Step Plan for Women Living with Multiple Sclerosis, suggests setting goals you might have previously thought were impossible, such as "I am not a person who wears red" or "I could never write a blog". Cohen suggests taking one of your impossible goals and begin to chip away at it, acting as if this behavior suits you. She points out that doing something you didn't think you could can lead you to discover you can!

The whole notion is to step beyond what you used to do and discover a new part of yourself that might otherwise stay buried if it weren't for the challenges you face.

*If you can, get a bed that adjusts so you can sleep better. –SR*

*This was more than a health issue for me. In the end, it was an indication that I needed to improve the way I handle "life situations", as they are inevitable as I age. I can rise to any challenge with family, business, and life activities, but was woeful in a case that had me at the center. –DP*

*I know that loneliness is one of the worst things. Feeling isolated, alone and depressed has led me to appreciate friendship far more deeply. –DC*

*I made a list of all that I was grateful for. It was easy to get absorbed in the challenges. –TE*

One of my mother's perspectives on challenging times is, "It could be worse." How true that is. We can always look around us and see others who face more significant challenges but staying grateful when our worlds turn topsy-turvy is a challenge in and of itself. As turmoil pulls our attention inward, it is natural to feel the tug of emotions and pain. Yet, focusing on something we feel grateful for helps buoy us during these tough times.

To encourage my gratefulness, I hang cards and pictures that others sent wishing me well on my home office wall. While my crisis has subsided, their wishes remain on my wall. Seeing the cards continues to encourage me and warms my heart.

In a moment when you feel grateful, create a list of what you are grateful for, even during this time of challenge. Then, when you feel down or out of sorts, you can look back at this list to help regain some balance. To help start you off, below are suggestions from others that helped them experience gratitude.

### Workbook Chapter 12 Pathways to Coping *Grateful*

Write down the people in your life you are grateful for and what it is they bring to your life to make it better.

| Person | What They Bring to My Life |
|---|---|
| | |
| | |
| | |

List things you like about yourself.

List experiences for which you are grateful.

> *Due to osteoarthritis, I can't do a lot of what I would like to do. I watch others run, do aerobics, get up and down from the floor with their children, and I feel envious. I am not a fan of envy, so I thank God that I can walk and work in my yard. –LE*

## Faith

> I *got angry with God. It was just too much. I still don't understand it. –LF*

Shifting out of the initial shock of our crisis gives us some time to reflect. Why did this happen? Could I have done anything to prevent it? What's going to happen next? These questions tend to spark a review of what we believe. We look for cause and effect.

It is human nature to seek patterns in our lives. Seeing patterns allows us to connect the dots of what we experience. Connecting the dots helps us attach meaning to our experiences. Finding meaning can give feelings of comfort and control or force us to question what we thought was true.

For example, if a dog bit us when we were young, we might be afraid of dogs. The dog bite (a dot) connects with the idea that we could be bitten again. The possibility we could be bitten creates fear. That knowledge and fear lead us to cross to the other side of the street when we see a dog approaching. When we walk on the other side of the street away from the dog, we aren't bitten, which reinforces the idea we should avoid dogs.

As we reflect on this example, we can see how walking on the other side of the road would make someone feel better, as well as not getting bitten. On the other hand, we know if we stay on the side where the dog is, there is a good probability we won't be bitten then, either. But when it comes to fear and trauma, risks are not what we usually want to take.

While the example is simple to understand, it applies to a variety of challenges. Simple or complex, our brains seek out reasons why things happen the way they do because if we understand the underlying why, we believe we can avoid bad things from happening in the future.

For many, religion, faith, and beliefs serve as a foundation to understand the world beyond what we can see. Crises increase the brain's desire to understand, often causing us to reevaluate our beliefs. This reevaluation leads some to stronger religious beliefs, while others experience a departure from their faith. Still, others seek reason and comfort outside of organized religion.

*My struggles forced me to contemplate what brings purpose and meaning to my life, and that included evaluating my faith. –FE*

## Strengthening Faith

*This experience brought us closer to each other and faith in God's plan for our life. –SJ*

Many religious organizations provide comfort through traditions, beliefs, and community. While the value of religious organizations can support individuals through typical days, they can take on deeper importance during challenging times.

*My faith grew immensely. I didn't fear dying. I felt an astonishing peace that comes from my faith. –BK*

*I pray daily and needed to talk to God a lot during this journey. –LW*

*My faith played a large part and I totally believed that it would be over soon. –KM*

*On a daily, hourly, and sometimes minute-by-minute basis, I begged God, Jesus and the Blessed Mother not to let me die. When I prayed the hardest, the prayers* *were answered, even if it was just in a small way, like the relief of a particularly bad symptom or fear. –MF*

*My faith helped me face my challenges with strength. –MR*

*I always considered myself to be a spiritual person, and that quality intensified during diagnosis, treatment, and afterward. My religious community and leaders were very supportive. I continue to see myself as a more spiritual person post-illness. –JN*

I *know that people were praying for me and my recovery, and I truly feel that it helped in my healing. –DH*

### Losing Faith

*To be honest, I was angry at God. I couldn't understand how this could happen to such a good person. I guess that means I still believe in a God/force, but maybe not. –BS*

When challenges are faced, it can create an upheaval in one's belief system.

*My faith and/or spiritual outlook are "diminished."–LT*

*I have to say that when it all first happened, I felt as if I were being punished. –GW*

*I wonder if miracles are real and if we may ever be spared one. I question my faith, especially when I see others with the same diagnosis embracing theirs as their child improves. –RR*

*I have a hard time going to church these days. –AR*

*I struggle with my faith. We did everything right. Why was she targeted? She had just gotten married and had her whole life ahead of her. –JG*

### Spirituality

*I'm a spiritual person rather than religious. I talked to God a lot, thanking him/her for the good fortune that it was found. I feel I'm the luckiest person. –MT*

Spirituality usually refers to a belief in something beyond what can be seen. Nowadays, when defining oneself as "spiritual but not religious," it usually means the person believes in some spiritual force and the power of connections with others yet doesn't observe any particular religion.

*From this experience, my perspective is that God, or a God-like being is all around us. A good feeling. –GM*

I *have become more spiritual over the past five years. –RZ*

*I had some unusual experiences that reinforce my belief that there is an energy/power beyond our earthly existence. When I was in the hospital, I felt a presence on the right side of my bed that I can only describe as angelic. Its presence gave me a sense of comfort and that I wasn't alone. –CS*

*Faith was not that important to me during my treatment, but I know that all my friends and family prayed for me to live. It made me realize prayer is helpful and that you don't have to pray to God. You can pray to comfort yourself. –LR*

## 13-Dealing with Others

We are surrounded by people. Some we feel close to, others not. Although we don't share everything with everyone, we do need one or more supporters with whom we can open up. Being too solitary feeds the trauma reaction and amplifies the urge to take flight or freeze.

When a medical challenge occurs, news spreads like the old childhood game of telephone. The information quickly makes the rounds as one person tells someone, that person tells another, and so forth. Sometimes the proper facts aren't conveyed or facts are shared with people we would prefer not to know.

I think of our lives as consisting of three tiers of relationships. 

- Tier 1 contains those to whom we are most close. This level may include a spouse, partner, best friends, and siblings. These are the folks with whom we share the most and want to keep aware of our experience.
- Tier 2 consists of people we consider friends, family (sometimes not), certain colleagues, and close neighbors.
- Tier 3 includes people we encounter but don't feel particularly close to, or with whom we don't share personal information. Many people at work fall into this category, as we want to keep a professional separation with some colleagues.

Being aware of whom you place on each level is helpful. Some people around us may think they are closer to us than we feel to them. While we can't control that, we can prepare what we will and won't share with each of the groups. That way, when you meet someone at the grocery store and they ask how you are doing, you can share as much or as little as you want based on what level the person is in. If someone is a Level 3 individual and says, “I heard you had heart surgery,” you can respond with “I’m doing fine now, thanks.” If you encounter someone who is on Level 2 and asks about your surgery, you might be more forthcoming. Preparing responses ahead of time can be helpful.

## Workbook Chapter 13 Dealing with Others

Write who is on your different tiers. Decide what you want to share with each tier, and how. Have an idea of how you might respond to someone in each tier when they ask how you are or how they can help. (For ideas, see the section titled “How can I help?”)

| Person | What to Share |
|---|---|
| Example: A neighbor up the street I rarely see ( tier 3) says, “I heard you’re sick.” | “Yes, I’m going through treatment, but I’m doing well.” |
|  |  |
|  |  |
|  |  |

*Some people whom I am not well-acquainted with asked for details that I was not willing to share. For example, I did not want out-of-town relatives on my husband’s side of the family to know any details. I am not close to them and do not see them. Although well meaning, they would not be a comfort to me. There is sharing and there is gossip; there is a thin line between the two. I am very open with my friends, but I like my privacy to be respected by more distant acquaintances. –MM*

How to handle inquiries in work settings brings up different issues. Some of us can work during our treatment. For those with chronic conditions, our need to involve employers in conversations can wax and wane. Knowing what you want to say and to whom, just like with Tier 1, 2, and 3 relationships, can help reduce distress and uncertainty as to what to say in the workplace.

The hope is that all will receive fair treatment, but it may be helpful to review the American Disabilities Act. The American Disabilities Act has some provisions and protections for those with diagnosed medical diagnoses and treatments.

*I had an extremely compassionate and supportive boss. She encouraged me to take all the time I needed. On my return to work, I had the practical challenge of being well enough to resume my job, but not healed sufficiently to twist and turn* *beneath a seatbelt. She arranged for a car service to ease the first weeks of my commute. This was a luxurious and unexpected kindness. –LO*

*People at work filled in for me on their own free time. –LL*

*My office was very helpful and understood that every third week, I needed to go for chemo.–KM*

### Concern for Our Loved Ones

Crisis is not experienced alone; there is a ripple effect. Our families and friends are impacted. While their reactions may be more delayed than ours, the impact is there. Those around us might not outwardly express their reactions directly to us, but the impact is there. A friend of mine with brain cancer said her husband never asked her how she was doing or seemed to understand her struggle, although she later found out that he talked to their daughter about his worries.

Two years after my diagnosis, my 31-year-old son called me in tears after listening to Taylor Swift's song, "Soon You'll Get Better." Through his emotions and Taylor Swift's words, he told me how proud he was of how I was coping with my experience. Some peoples' words and emotions emerge on a different timeline than ours.

Just as they worry about us, we worry about them. A tumultuous time ensues for all when a crisis occurs. Routines change. Finances are impacted. Energy levels shift. Attention fluctuates. Above all else, no matter what happens, we want our family and friends to be okay.

*It was so hard for me to see the effect it had on my preteen son. He was very frightened and freaked out. He acted out in school. It was a very emotional time for both of us.–RG*

*I was concerned about how my diagnosis would affect my husband, children, and grandchildren. I very much want to spend quality time with all of them. My oldest son and his family have moved to the area, and I treasure our frequent times together. I want to live to see my grandchildren grow up and thrive. –MM*

## 14-What Helps and What Doesn't During Treatment

During treatment, having specific support is helpful. Most of our friends and family want to be helpful, but don't know what to do or say, so they end up saying, "If you need anything, just let me know." While the comment is sincere, it leaves us uncertain about what to say back to them. Many times, we don't even know what we need until the need is upon us.

Those who have walked in our shoes have experienced what helps and what doesn't. Through their experiences, we can explore what we want and don't want. Knowing what we want can help us know what to say when someone says, "What do you need?"

### Support That Is Helpful

*People dropping by made it more pleasant when I was in the hospital. –DH*

*Two close friends organized much-needed meals. Caring friends signed up and dropped off dinner in the cooler at the front door. It was so helpful to have the meals and have them coordinated by someone other than us. –CS*

*There were plenty of times I didn't feel like talking about my health, treatment, or what I was going through. I was grateful for my friends who didn't push me to talk when I didn't want to. –XR*

*I didn't need people to be there 24/7, but I did appreciate phone calls and cards. –MT*

*They showed their love for me and were present. Cards and emails were all appreciated. –MF*

*Receiving practical support, such as raked leaves and shoveled snow, was so helpful. Such favors and gestures became amplified in their meaning during this time. –LO*

*My dearest friend kept our dog for us whenever I was in hospital (a total of 28 days). Not only did it save us a load of money, our dog was happy and my husband could come and go to the hospital whenever he needed to. Luckily, they love my dog and he loves them. –SR*

*People dropped off food, books, music, and talked to me about things other than illness. –BR*

*Friends came to visit, knit, or discuss books we were reading. Sometimes we would just hang out and chat. It gave my husband a break that he really needed. I needed the distraction. –SR*

*One friend sent me a video a day to check out. Sweet. –GM*

*I had an aide three days a week who came for four hours a day. She did laundry, took me grocery shopping, and stayed with me when I was really sick. That was very helpful. –MT*

*My husband was wonderful. He went to every appointment with me. He supported my decisions and helped me talk through the thinking that I had to go through to make each decision. His theory was that it was my body and I got to make all the decisions. I will always be thankful to him for that. –SR*

*My husband's openness and acceptance of bilateral mastectomy as a choice for treatment was so important to me. He was a "breast man," and mine certainly attracted him when we first met. Throughout our relationship, my breasts had brought both of us much sexual pleasure, yet he made it clear that he'd rather have me without breasts than a roomful of them without me. –LO*

*My wife was there for all the treatments in spite of my "I'm fine" attitude. –DP*

*My husband made me a deal. He would cook delicious food for me. I would try to eat what I could. If I couldn't eat, he would not force me, nor would he get his feelings hurt. I think I am the only person in history who gained weight on chemo. I had made him the same deal when he was having chemo and then he returned the favor. –SR*

*I wanted to talk about the "what if" scenarios, particularly what if I died. Only my rabbi would listen. I didn't think I was really going to die, but I wanted to be prepared. –LL*

*"I'm thinking of you." That is all that needs to be said. -TZ*

### What Doesn't Help

*"At least depression isn't life threatening." Oh, really? –TS*

*Whether I can have children of my own or not remains to be seen. The cervical cancer treatment can affect carrying a child into this world. It doesn't help when people ask why I don't have children since I've been married for over four years. –AB*

*I felt lonely because people didn't check in. I think the solution is either emailing or texting something like, "Just checking in. I'm here to listen or make a meal or whatever, if you need me, but I understand if you'd rather be left alone right now." –SH*

*I wish that more people had been aware of my husband's suffering and offered him support too. –JN*

*Don't avoid me. –RM*

*Some people don't know how to process trauma. They ended up ignoring me or leaving me behind. –AB*

*It astounded me when people would tell me why my situation wasn't so bad. When I gave birth to a much-wanted child who was stillborn, I was frequently met with, 'The baby would have been disabled'. 'At least you know you can get pregnant'. –TZ*

Treatment is a journey no one wants to take. It is a prolonged experience of trauma, and being aware of our tendencies to fight, flee, or freeze can be useful. Navigating side effects and processing emotions are a crucial part of our experience and are inextricably intertwined with accepting support from the circles of relationships and networks in our lives.

There is no right or wrong way to get through a medical crisis. We didn't opt to go on this journey — but it's important that we show up.

### Cindy's Journey *Ring That Bell*

I see the seven-year-old faces beam with pride on receiving their "participation" award at the end of the Little League season. The merits of receiving a reward for just showing up have been debated over the years, as some claim giving an award for lack of true achievement makes our newer generations soft, less motivated, losing out on the pride of accomplishment, and the like. However, sometimes showing up is exactly what we need to do.

I finished radiation today: 20 days, 20 sessions, 20 series of a collection of rays pointed at specific locations in my body. I didn't feel the rays as they invisibly penetrated my body, but I can tell it has helped. My bone pain is less. Yes, there are some side effects. Could I get more fatigued? Well, radiation proved I could.

Bonds form quickly in the women's waiting area as nonverbal understanding is created. No hair: breast cancer. Robe open in back: lung cancer. Pants: uterine/cervical cancer. Then there is me: full head of hair with the robe open in back, reflexively moaning as I lean back in the chair…multiple myeloma.

Nevertheless, it doesn't matter why one is in that waiting room; we are sharing an experience none of us want.

Over the course of the month, I came to recognize the regulars with whom I share similar appointment times. Then there are the new folks, who sheepishly ask, "Do I take my purse with me?" "Do I have my gown on right?" "The key isn't working in the locker." "Does it hurt?" Such inquiries are quickly responded to by those of us who are more seasoned, as a couple of visits gives a sense of knowing and expertise. Lessons are quickly learned here.

Across the sessions, I hear the clanging of a bell. A large brass bell attached to the wall is rung when one completes the requisite radiation sessions. The bell rings and the radiation therapists applaud, quickly joined by those of us in the waiting area. A rite of passage.

While I supportively cheer for those ringing the bell, I feel funny. Do I want to ring the bell? Seems silly. What did I do? I didn't have regular workouts in order to complete the race. I didn't help anyone. I didn't pass a test. I didn't leap tall buildings in a single bound.

Did I do anything bell worthy? They tell me to be there at 9:30, so I am. I sign in, change my clothes, wait to be called, and chat with the therapists as they line me up for the treatment. None of that seems bell-worthy.

What did I do that was bell-worthy? As I move through treatment today, the answer resounds through me. I showed up.

By showing up, I made a statement that I am giving healing my best shot. By showing up, I recognize and appreciate the advances brilliant minds have created. By showing up, I thank the doctors, nurses, therapists, and technicians for giving of themselves. By showing up, I support others who are "in waiting." By showing up, I moved forward.

So, get out of my way. I am going to ring the damn bell!

## 15-Shifting Ground

*It's still a roller coaster, but now the hills are smaller. –CS*

Our emotions fluctuate during a crisis. Afterward, the intensity may ease, but we are still processing what happened, and coping with the challenges. Our experiences cause us to feel vulnerable even though we are out of immediate crisis and danger. Our brains and emotions haven't settled into trusting the new ground we stand on.

### Avoidance

*I have to deal with the daily effects of treatment. I try not to dwell on it. –GP*

Six months after my stem cell transplant, I had an appointment with my physician at Dana Farber in Boston. My husband suggested we stop at Brigham Women's Hospital to show the staff how well I was doing. As much as I wanted to thank the staff for their expertise and care, the mere thought of walking into the building caused a flashback of lying in the bed tethered to needles and tubes while the side effects of the interventions coursed through my body. Sometimes, avoidance is the way to go. Not all situations need to be relived.

### Anger

*I should be back at work and playing tennis by now. But every step through this "routine" surgery, there has been another setback. I'm so angry. –FF*

Anger is good! Anger is often a healthy reaction to upsetting circumstances. One of anger's greatest aspects is its ability to be a mobilizer. Anger can propel us to act to change our circumstances. Anger can lead us to reclaim parts of our lives. Managing anger and expressing it in constructive ways is essential.

*I think the experience hardened me in ways. I wish it hadn't. My anger lingers. –DP*

### Anxiety

*The following five-year period, I experienced high levels of anxiety that appeared to be the result of my new (blood) operating system. During the process of determining the right meds for my anxiety, I was extremely concerned that I would have this debilitating anxiety for the rest of my life. This was very scary. –GM*

Anxiety is a common reaction to uncertainty. Medical journeys are a natural feeding ground for anxiety, worry, and fear. Most of us live our lives knowing we are not immortal, but when our physical health is threatened, we face immortality in a real and impactful way. Will I live? How long will I live? Will this come back? Will I have another heart attack/stroke/accident? The list of "what ifs" that floats through the mind becomes lengthy and real.

*I was relieved my treatment was done, but also scared about what would happen next. I worried about money, since I couldn't work for a year. –LR*

*I was so relieved to be done with treatment, but also wondered if they got all the cancer cells. What if one escaped and went to another part of my body that wasn't checked? –DH*

### Disappointment

*When I had my breast reconstruction, my plastic surgeon also reconstructed my scalp (due to melanoma). I no longer have a large cancerous spot on the top of my head, but I can't wear my hair as short as I used to because the scars show. I have to wear a hat when I go outside. I hate hats. –SR*

Disappointment occurs when we expect something different than what has happened. After undergoing surgery, recovery, treatment, and more, we assume our lives and bodies will return to "normal." Sometimes, they do. Other times, our lives and bodies are altered, and we must adapt. While adapting to unexpected changes is essential for overall well-being, accepting outcomes is not without disappointment. It's okay to be grateful you are alive and disappointed that not everything ended the way you hoped.

*I thought I would bounce back to my old self right away, but that hasn't been the case. My hair is slow to come in, and the neuropathy in my feet and legs hasn't gotten better. It is so disappointing. –MT*

*My breast is sort of deformed. I don't like that. It's a small price to pay for good health, though. –MR*

*In some ways, I found it depressing when treatment was over. The radiation oncologist told me that was normal. I had been proactive, and now I was in a passive stage. –MB*

## Waiting for the Other Shoe to Drop

Anticipating that “bad news” will come your way again is a hallmark sign of a trauma experience. The very nature of trauma is experiencing something threatening that is out of the ordinary. We imagine if we stay on alert, we can prevent or head off future trauma. At the same time, our rational thinking knows that sometimes events occur out of our control. Taking action to help protect ourselves from negative future experiences helps us feel in control and pushes back the fear.

To combat fear, some choose to change their eating habits and amount of exercise. Others add outlets that increase comfort, such as meditation, praying, or being in nature. Finding habits that support you brings greater ease.

*I exercise and take my meds but think of congestive heart failure every day. I am always concerned about my insurance since I am self-employed. My insurance and medications are expensive. –BR*

*As Victor Frankl wrote in Man’s Search for Meaning, the only thing we can control is our attitude in life, whatever the situation or circumstance we are facing. –RGW*

*I am fearful that the cancer will return, but I also have gone on with my life. –SR*

*I am still worried that the cancer could reappear. My mom had breast cancer twice in her life and then was diagnosed with Stage 4 lung cancer and died within four months. It’s a fear that lives within me. –RG*

## 16-Managing Emotions

We have some moments when we feel free, yet other times unsettling emotions interrupt our days. What can be done when we are bothered by emotions that pull us away from living more contentedly? My mind flips back to when I worked with a young man, Jason.

Jason’s life was interrupted by anxiety, particularly at night. As he climbed into bed, his mind began to be bombarded with worries. His worries took different forms: what happened during the day, what the next day would bring, analyzing every interaction he had and thinking about what he wished he had said instead. The worries mounted triggering high levels of anxiety. Different strategies to mitigate his angst were met with minimal success.

Jason explained he didn't want to forget what he worried about because he was afraid he would miss something important. And so, we created Boxes on a Shelf.

First, we created a list of the categories of his worries (e.g., what he had to do, things he said he wished he hadn't, health, random worries, etc.). These categories were labels he put on imaginary boxes. At night, when disruptive thoughts and emotions burst through, his job was to determine which box each thought should go into. He told me how he how he would lay in bed as the events of the day swirled through his mind. He seized one and determined what category it fell into. Once he decided on the category (e.g., unnecessary worry), he imagined the box with that label and visualized placing the worry in the box. If a worry popped up that didn't fit into any of the boxes he had already created, he visualized a new box, created a label, and put the worry in that box. As his mind began to empty, he imagined placing the boxes on a shelf in his closet, closing and locking the closet door until morning.

In the beginning, he actually made boxes. He took old shoeboxes, Amazon boxes, anything he could find, and labeled them. When the thoughts and feelings created distress, he took the box, opened the lid and made a motion with his hand as if he pulled the thought from his mind and placed it into the box. As time went on, he didn't need to use real boxes. Through practice, he could visualize the boxes and imagine putting his worries into the proper box.

What helped Jason was being able to set aside his worries and place them somewhere outside of himself. He knew his worries and thoughts would be waiting for him in the morning, should he want to act on any of them. But practicing this technique led Jason to sleep more soundly. Soon he found that in the morning, he didn't need to retrieve or think about the "worries in the boxes."

## 17-Triggers

*Doubt and worry are always in the background, and those feelings can be triggered by a ringing phone, a twinge or ache somewhere in my body, or the verbal angst that my children sometimes express. It's like a part of me relives the trauma. –JN*

Most of us live life in segments. We are taught that life has stages: infancy, childhood, adolescence, young adulthood, and beyond. Time is also experienced in segments. For many of us, our internal calendar year is set by the start and end of the school year, and even by the length of classes. When I was in high school and college, most of my classes were 50 minutes long. Even now, many years later, a 50-minute clock ticks inside me. Toward the end of a 50-minute time span, my attention starts to wane. Long ago, my brain learned that at the end of 50 minutes, it is time to move to a different activity.

Viewing life and time in chunks influences how we look at our health journeys. We think of health crises as falling into distinct stages: diagnosis, treatment, and beyond. But our emotions don't follow such a predictable pathway. Emotions ebb, flow, and spike from a variety of triggers. A trigger is something that sparks a memory of a previous experience. The trigger connects you to the past, making you feel like you are experiencing it all over again. The re-emergence of emotions through triggers is part of what occurs once the main crisis is over.

> *I think that every ache and pain is a side effect of something related to the cancer. It triggers me all over again.–SJ*

## Pain as a Trigger

> *Every time I get a headache, I wonder if I have a reoccurrence of a brain tumor. –JZ*

Some triggers are predictable, while others catch off us guard. One of the most predictable triggers is pain, because pain and emotions ignite overlapping parts of the brain. Therefore, when we feel pain, we feel a surge of emotions associated with that pain. Not only does one feel the physical pain, but also the emotional distress linked to the pain and trauma of what causes the pain.

> *I've been living with this chronic pain and life-altering diagnosis for over 40 years. Some times have been worse than others, yet I find I have meltdowns that come out of nowhere. –LE*

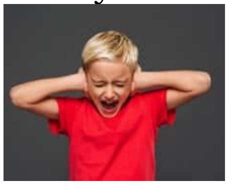
> *Every time I have to have blood work done, I worry. I tend to wake up around 3:00 a.m.: the time THE call came in telling me to go to the hospital. –LL*

## Sensory Triggers

*When I get behind the wheel of a car, I get anxious because of the accident. Being near a truck causes extreme stress because most of the material in truck beds is not tied down. I can still see the metal piece flying through the air and breaking my windshield, causing my multiple surgeries. –CK*

Our suburban yard backs up to the woods. It's not unusual to see a family of deer roaming through our yard. These deer seem quite content as they munch their way through the garden I've painstakingly nurtured over the years. My presence doesn't cause them to flee, but the shaking of a paper bag I wave like a crazy woman sends them leaping back to the depths of the forest. What is it about the sound of the bag? Why does that bother the deer, whereas standing in close range barely causes them to look up? Dr. Leonard Perry, an Extension Professor at the University of Vermont, wrote[1] that deer sense potential danger when unexpected motions or sounds occur. Unexpectedness is the key. My presence isn't unexpected to these practically domesticated deer, but the sound of the paper bag is unique, causing them to flee. My paper bag is the deer's mountain lion.

Touch, sound, sight, taste, and smell are our basic input sensory systems. When our sensory systems receive information, our brains take note. Our sensory sensitivities vary. One of my grandsons, Porter, covers his ears when the public bathroom hand dryer turns on. Another grandson, Rowan, was literally knocked down by the burst of air emitted from the hand dryer and didn't miss a beat. The loud noise of the dryer rankles Porter's nervous system, creating his startle response, whereas Rowan's system is unfazed. After a few exposures to the loud hand dryer, the mere sight of it causes Porter to cover his ears as his brain prepares him for the sensory overload. The links between what he sees (hand dryer), the sensory overload (noise), and his emotion (distress) have been cemented in his mind.



As adults, we've learned to handle loud and annoying sounds, but when we undergo a novel situation, our brains become like a child's (or a deer's). We're on alert. Our brains link sensory input with distress, and the mere exposure to the sensory stimulus later can precipitate a reaction. For example, some people hate the smell of hospitals. Is it the actual smell that is unpleasant, or is it the link that sits in our brain between the smell and the emotion we felt when we visited someone in the hospital, saw someone ill, or was a patient there? In these moments, we become like the deer. Sudden and unexpected sights, smells, and sounds trigger feelings related to medical journeys. Like the deer, we want to bolt.

Not all triggers can be avoided, but there are some strategies to help ease sensory triggers. For example, breathing exercises can ease the reactions the trigger is igniting. Distracting yourself with a positive sensory experience (e.g., music, favorite food, movement) can spark the brain to shift gears. When identifying a positive sensory experience to take the place of a noxious one, stay in the same sensory category. If it is a smell, expose yourself to a positive smell. For example, if the smell of hospitals is a negative, engage your nose and taste buds with peppermint gum. For Porter and the hand dryer, I had him close his eyes so he couldn’t see it, and I sang to him so he has something else to listen to other than the blasting air of the dryer.

Below is an example of a chart to become aware of your own triggers and coping techniques. Go to:

**Workbook Chapter 17 Triggers *Sensory Triggers***

| I Am Triggered by These | | Plan/Techniques to Help |
|---|---|---|
| **Smell** | | |
| **Smell** | | |
| **Sound** | | |
| **Sound** | | |
| **Taste** | | |
| **Taste** | | |
| **Touch** | | |

| | | |
|---|---|---|
| **Touch** | | |
| **Sight** | | |
| **Sight** | | |

*I had to change doctors. After three miscarriages and two failed IVF treatments, I couldn't go back to the medical office building without having a panic attack. Just seeing the building set off emotional reactions. –SS*

*Driving down the road, someone laid on their car horn. I jumped in my seat while swerving my car closer to the side of the road, only to learn the horn wasn't for me. I am so jumpy when something unexpected happens. –CS*

## Anniversary Triggers

The anniversary of a diagnosis, accident, or death can be a predictable trigger. Flipping the calendar page and knowing that the "date" looms ahead sends emotions coursing through us. Sometimes we don't even realize a certain turning point on the calendar is approaching, but our body and deeper memories know this was a critical time. A surge in emotions related to time is referred to as an "anniversary reaction."

Anniversary reactions are an interplay between the brain and emotions. The brain stores the event in the memory in order to try to protect us from future pain and shock. Yet as we learn in life, we can't always protect ourselves. People get sick, die, experience violence, and suffer. When the anniversary of those moments looms, the emotions related to the memories are sparked and the old feelings surge forth.

The one advantage of anniversary reactions is that we know which dates might be challenging and can take action to cope. Suggestions to help lessen anniversary reactions include:

Make specific plans for the day/time.

Some do better with recognizing the day with a ceremony or spending it with family/friends; others do better distracting themselves by traveling, being outdoors, or immersing themselves in an activity.

Some want the support of family and friends; others prefer to be by themselves during these anniversary times. Drawing within feels protective to them.

## **Workbook Chapter 17 Triggers** ***Anniversary Triggers***

What works best for you? Jot down some dates that may trigger you and what you can do to support yourself.

| Date | I Plan to… |
|---|---|
| | |
| | |
| | |
| | |
| | |

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[1] http://pss.uvm.edu/ppp/articles/deerdeter2.htm

## 18-Rebuilding

*I don't like thinking of myself as a "patient" anymore. –TJ*

As we move away from the peak of our health crisis, there can be a period of mourning over what has been lost during the process, as well as a greater appreciation of life and its goodness. Eventually, it's time to focus on rebuilding.

For some, their lives look and feel similar to the way they were before the crisis. For others, the changes require redefining their identity and how time is spent.

Whether we are aware of it or not, we all have ways in which we identify ourselves. During this time of rebuilding, our identity and activities take shape anew.

### How Do You Want To Be Now?

Each of us is made up of a collection of personality characteristics that make us unique. While you might have the same personality traits as someone else, everyone will have different amounts of each trait. The combination and amounts make you unique. Knowing your personality traits is helpful during many times of your life, but it is particularly important now. The better we know ourselves, the easier it is to figure out how to move to more solid ground.

Identifying your personality characteristics or traits is a good place to start. First, think back to what you were like when you were in elementary school, as children tend to be closer to their pure selves (also known as soul self). Picture yourself back then and write down traits you exhibited as they pop into your mind. Try not to censor or evaluate them; let the words bubble forth. How would you describe yourself back then?

### **Workbook Chapter 18 Rebuilding *How Do You Want to Be Now***

Personality characteristics/raits

| | |
|---|---|
| Example: adventurous | |
| | |
| | |
| | |
| | |
| | |
| | |
| | |

If you have difficulty generating words that describe you, there is a list of character traits in the Appendix.
Looking over the list you generated, write the five or six words that best capture the real you/soul self of your childhood.

Next, list words that describe you as a result of your medical journey. Again, don’t overthink, go with your first reaction.

Compare the first list of words (your “child self”) and the list related to the present. What traits are on both lists?

Which traits are different?

Are there any on the child list that you would like to recapture?

Are there any current traits you would like to build on as you move forward?

__________________________________________________________________

__________________________________________________________________

Any traits you would like to let go of?

__________________________________________________________________

__________________________________________________________________

__________________________________________________________________

A client of mine identified her top five “child” traits as happy, reader, shy, achiever, and hard worker. Her current list overlapped with hard worker. The other four from her current list were worrier, uncertain, strong, and determined. As she looked at the current list, she felt she had become stronger and more determined from what she went through, as well as from other situations in her adult life, but she didn’t like being the worrier she had become. She believed worrying and feeling uncertain were a direct result of having cancer. Wanting to change, she decided to take Tai Chi classes to feel even stronger and more confident. She soon found that building on those qualities lessened her worry.

### Cindy’s Journey *Not the Fun One*

We all have labels. Sometimes the labels are flattering, other times not. The angst of teen years is heightened as our self-consciousness clings to others’ opinions. But it isn’t just peers that have labels for others; parents do too. The labels might be overt or subtle, but they are there. If you are asked to describe someone, usually the first word offered is one of the labels used to categorize the person. Try it. Make a list of friends, family members or colleagues and write two words you would use to describe them. Those two words make up the labels you hold in your mind.

My two sisters, Debbie and Betsey, and I have eleven children in total. My niece, Jennifer, leads the pack of cousins due to her inherent leadership skills and because she is ten or more years older than the rest. Jennifer is, and always has been, a kind, thoughtful, competent, and all-around lovely person. I love Jennifer. Fond memories of carrying her around the backyard to show her the fruit growing on the trees, and playing Crazy 8s when she got older, cemented Jennifer in a special place in my heart. So imagine my surprise when she was about 12 years old and she told her friend she couldn't come over that night because her aunt was visiting. Her friend asked which aunt was visiting. "Cindy's here," replied Jennifer. Then I heard Jennifer say, "No, not the fun one. The fun one is Betsey." There you have it, folks, one of my labels: not the fun one. Betsey is the fun one.

Jennifer and I share this memory from time to time with a smile and my acknowledgement that Betsey was, and is, the fun one. Betsey has a quick wit, creative mind, and unique way to capture the humor in situations. I have benefited from Betsey's positive outlook and ability to bring joy. Throughout the ups and downs of my treatment, I would call Betsey when I wanted to hear about normal life, projects, and honest opinions, or just revel in the connection we share. In my darkest of days, Betsey made me laugh. She didn't have to try; it's just her caring nature and the clever way she embraces life's moments.

We can't all be a Betsey, but we all have gifts that we bring to others.

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*Do I wish this never happened? Absolutely. Three cancer diagnoses before I turned 31 threatened my identity. I had to find myself again. I ended up coming out ahead. –AB*

Richard Tedeschi, Ph.D. and Lawrence Calhoun, Ph.D. refer to growth after crisis as post-traumatic growth (PTG). They developed a scale that evaluates post-traumatic growth, the Post-Traumatic Growth Inventory, or PTGI.[1]

Tedeschi and Calhoun talk about five areas of positive growth from trauma.

Appreciation of life *The air smells sweeter, food tastes better, and I seek out the company of the positive and loving friends and family who I treasure. –MM*

Relationships with others *Let those who love you in. I was selfish in a way and didn't think about their needs to be part of the healing process. –DP*

New possibilities in life *I feel my experience made me more caring and thoughtful, particularly when I hear of others going through some type of illness or treatment. I have a more positive attitude and try not to let things out of my control stress me.–DH*

Personal strength *You can do it. It's terrible, but it's doable. You are stronger than you think. You can do it. –BR*

Spiritual change *My faith grew stronger. I have always believed in God. I feel that this spiritual being is watching over me along with the angels in my life. I feel truly blessed again and again. –RG*

It is challenging to think about the positives that come from trauma while we're going through it. One of the positives that evolved for me was deep gratitude for others outpouring of support. I have hundreds of cards hanging on my office wall. Their love and encouragement bolstered me. Seeing these cards and pictures continues to warm my heart and lighten my load.

### Workbook Chapter 18 Rebuilding *The Gifts of Trauma*

What are three positives your crisis brought about?

1.

2.

3.

Because I am so awed by others' kindnesses, my experience has encouraged me to take the time to send cards, check in with others, or make a meal in others' times of need. Not only does it help them, but also it makes me feel good to pay it forward. If you want to build on any of the three positives you identified above, list what you can do to continue to benefit from them.

1.

2.

3.

*Going through a cancer diagnosis at 25 was one of the best growing experiences of my life. I had to step back and take a close look at how I lived my life. –CL*

*There's no other way of saying it. My husband gave me an ultimatum. He had asked me numerous times before to stop drinking and there was even a family intervention several years before that, but when he came to me and said he could no longer watch this and be part of it, I realized this was my rock bottom. I was going to lose my family. In-patient treatment, AA meetings, yoga and more lead me to a new way of life. I combined my nursing background, own experience with alcohol use, and a coaching program, resulting in being certified in both wellness and recovery to coach women in the early stages of recovery. I want to help support women who are climbing the mountains. https://humblewarriorwomen.com –JR*

## Rebuilding Activities

Hobbies and activities enhance our quality of life. Doing something you enjoy has psychological benefits, like improved focus, happiness, and a longer life. It has been found that engaging in a hobby or area of interest for at least 20 minutes a week reduces stress. [2]

Hobbies also benefit our performance at work.[3] In fact, “How do you spend your time outside of work?” is often a question recruiters ask of job candidates.

Throughout life, our interests and hobbies change. Interests may be creative, athletic, learning, or something distinctly personal. A hobby can be something you do alone or with others. The key is doing something that is meaningful and that you enjoy.

I am reminded of the first time I saw a group of women wearing purple and red hats. I asked them about their hats, and they explained they were part of the Red Hat Society, which celebrates the power of women supporting each other and enjoying life. They certainly did seem to enjoy the gathering as laughter punctuated their time together. Meaningful activities can be as simple as that: wearing a certain color and being with people with similar interests and enthusiasm for life.

Indy Summers listed 23 Hobbies Guaranteed to Beat Stress in a Thrive Global Community publication.[4] While her list is not comprehensive, it gives our thinking a jumpstart. Choose activities below that might interest you and indicate what your next step would be.

### Workbook Chapter 18 Rebuilding *Activities*

| Hobby | Next Step |
|---|---|
| Start a collection | |
| Explore more music | |
| Start puzzling | |
| Get a coloring book | |
| Take up journaling. | |
| Take care of plants | |
| Get a pet | |
| Read more books | |
| Try knitting | |
| Paint by numbers | |
| Bake desserts | |
| Play an instrument | |
| Play cards | |
| Watch a documentary | |

| | |
|---|---|
| Rebuild a classic car | |
| Learn a language | |
| Go camping | |
| Volunteer in the community | |
| Start running | |
| Explore the art world | |
| Practice origami | |
| Pursue physical activity | |
| Go to dinner with a foodie | |

*I wanted to do something fun and different. I gathered a group of friends together to attend a local Paint Nite®. I knew this would be a good time despite not being at all artistic. I'd be with people I enjoy. Seeing my painting made me laugh, as mine looked little like the instructor's or my friends'. I needed to laugh. –CWS*

## Mindfulness and Meditation

Mindfulness and meditation are helpful in the rebuilding process. While these two terms have surfaced frequently in recent decades, their histories stem back thousands of years in both religious and secular communities.

Jon Kabat-Zinn, Ph.D., is well known for bringing mindfulness and meditation into the mainstream through his work. His work in the stress reduction clinic he established was featured in Bill Moyers' PBS Special, Healing and the Mind, and in the book of the same title.

Mindfulness is a quality of consciousness or awareness. Being mindful is paying attention to the current moment. Mindfulness involves noticing the world around us without judgment. For example, if you are driving down the road and a fellow driver weaves in and out of traffic, one reaction is to lay on the horn and hold it down well after the driver passes. When the moment has passed, we continue to feel the frustration, fear, or anger the situation sparked. The driver moves on, yet our blood pressure stays elevated, distress continues, and our mood is colored by the event. Employing mindfulness in such a situation might include recognizing the thoughts and feelings the situation triggered and then letting them fly away in an imaginary balloon.

Mindfulness helps create balance in our body, brain, and emotions. When our systems are in balance, we experience increased healing, ease, and joy.

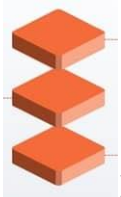
Meditation is a technique that builds on the idea of mindfulness. There are many different types of meditation, and people often try more than one to find the practice they like best. Medical News Today lists seven types of meditation and a description of each.[5] When pursuing meditation, it’s important to find which type of meditation suits you.

Not all meditation techniques are done in silence. I have found that guided meditation is easier, particularly for those newer to meditation. In guided meditation, someone talks you through a visualization or meditative exercise. Using apps is helpful because it can be done at almost any time and place. Apps that many find helpful as of this writing include Stop, Breathe and Think; Calm; Headspace; and MeMoves.

> *Meditating was an important change that came out of all of this. Meditating was part of setting my intention to move my life forward in a positive direction. –CL*

## Relating to Others

As we rebuild, our relationships must also find a new balance. Following treatment, those around you want to see that you are okay and healed. They are quick to move past the crisis, and want you to, as well. It is not a lack of concern or caring on their part; seeing you continuing to be in need or not well heightens their distress and sense of helplessness. As a result, some people stop asking you how you are and want to assume that all is well. Others continue to ask, and it helps to have a predetermined response to offer.



Prior we identified three tiers of relationships. It is helpful to review those tiers and create a set response you can give when someone asks how you are. As you adjust to invisible impacts, consider how and if you want to share them. Level 3 acquaintances may not need to know.

Level 1 consists of those we are closest to. This level may include a spouse, partner, best friends, and siblings. We share the most with and want to stay close to these folks. Responses in this area tend to be the most specific. Sample responses include It’s hard to adjust to the changes my body demands. I worry about what can happen, but it doesn’t preoccupy my thoughts like it used to. My pain is still bad, so I’m sorry if I get impatient. I feel so much better. I am relieved.

### Workbook Chapter 18 Rebuilding *Relating to Others*

Jot down responses you feel comfortable giving to the three levels of people.

**Level 1** is made up of those we are closest to. Responses in this area tend to be the most specific. Sample responses include "It’s hard to adjust to the changes my body demands". "I worry about what can happen, but it doesn’t preoccupy my thoughts like it used to".

________________________________________

________________________________________

________________________________________

**Level 2** consists of people we consider friends, family (though sometimes not), certain colleagues, and close neighbors. Responses in this area could include I still have some challenges, but I am much better. I’m holding my own. I’m feeling well. Jot down responses you feel comfortable giving to this group.

**Level 3** includes people we encounter but don’t feel particularly close to, or with whom we don’t share personal information. Responses in this area could include All is moving along. I feel so much better now. Jot down responses you feel comfortable giving to this group.

## Adapting at Work

When and if you can return to work, you might need a modified schedule. Clearly stating your needs with your manager or human resource representative is important so expectations aren’t muddled. Work hours may need to continue to accommodate doctor appointments, downtime, etc. Some positions allow working remotely or shifting work hours to meet your needs. Think about what you need and who needs to know what.

## Workbook Chapter 18 Rebuilding *Adapting at Work*

Identify what you need at work, who needs to know what you're going through, and what you can say.

| What I need | Who needs to know | What I can say |
|---|---|---|
| | | |
| | | |
| | | |
| | | |

## Rebuilding Keeps Evolving

Growth and life evolve, and this time is no different. Adjusting requires integrating experiences and being aware of where you are and how you choose to live now. Below are some additional resources that can support your rebuilding.

Inheritance of Hope contains resources for parents who have a child with a life-threatening illness. It offers suggestions as well as where to apply for wish-granting organizations that can offer financial assistance to your child, a vacation getaway for the family, and more.[6]

Masumi Goldman's Rise and Thrive: A Guide for Transforming Your Mood, Cultivating Inspiration, and Living Vibrantly with Chronic Illness.[7]

Craig Svensson's When There Is No Cure: How to thrive while living with the pain and suffering of chronic illness.[8]

Ilana Jacqueline's Surviving and Thriving with an Invisible Chronic Illness.[9]

Kimberly Rae, Sick and Tired: Empathy, encouragement, and practical help for those suffering from chronic health problems.[10]

All moments in our lives change us. Positive times bring us joy and strengthen us. Predictable days allow us to feel a rhythm. But it is the times of greatest challenge that move us forward. Challenges push us to reevaluate where we've been, how we've changed, and how we want to rebuild on firmer ground to be our best selves.

### Cindy's Journey *I Don't Want to Be Normal*

It has been three years. Three long years. Three short years. Through it all, I believed I would never take anything for granted. I would feel how music pulsates every cell into a blissful rhythm. I would hold onto an appreciation of my body and maintain an awareness of what it needs. I would re-experience gratitude for others' love and caring. I would continue to feel the spirit of the universe. I would forever appreciate what I've been through and how I fought.

But, as the days pass and routine sets in, the purity of my intentions wanes as mundane irritations, annoyances, and sorrows surface. When I falter, I try to recapture the clarity that the crisis brought and orient myself back to that place of gratitude. Sometimes I am successful and the sails are righted once more. Other times my ego knocks too loudly and I slip away from my goal.

I don’t know what will happen as I move through more days. But I do know I don’t want to return to normal. I want to be  better.

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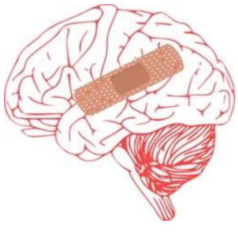
## Changes in How We Live

*If I do too much, my brain goes haywire. I get a fuzzy, numb feeling in my brain and I can’t think.–CS*

We are often anxious to resume the routines of our life. Not only do we desire normalcy, but our co-workers, families, and friends look to us to pick up where we left off. While some are able to return to a life similar to that before the crisis, for many the path is not as straightforward, and changes are permanent. We often don’t know how our lives are going to change until it happens. One thing is clear: healing and coping take time, and some of the healing is neurological in nature.

Health journeys affect different parts of our bodies, brains, and emotions. Our age, overall health, and pre-existing conditions complicate or ease our way. Medical personnel are cautious about telling us too many different possible outcomes because their focus is on healing and not overwhelming us with too many “maybes.” While we want medical personnel to be experts on how we can heal and reduce our symptoms, we need support to manage the hurdles that come along, even after the initial crisis/diagnosis/treatment/surgery is over.

Professional health organizations, such as the American Cancer Society and the American Heart Association, have links on their sites that present information and support for adjusting to both the obvious and the invisible changes in our lives that treatment brings. Hospitals, larger medical offices, and communities also offer support and information.



*I have memory loss, as the primary site of the surgery was where memory is stored in the brain. –JZ*

*After treatment, I still had to be extremely careful of germs. I became ultra-sensitive to them and worked very hard to avoid what I could. My fear of the unknown or if I was exposing myself to something I didn’t realize was always on* *my mind. Even my kids are aware. They became ultra-sensitive to where we are and who is around us. We can be in the food store and if someone coughs, they notice right away and we leave the aisle. –LL*

*Alive and yet there's grief. Grief over the years I've spent in surgery, on-going treatment, and healing. Grief over the restrictions I will have for the rest of my life. Grief over how doctor appointments pop up on my calendar as if they were a hobby. Grief over losing the naivete that I'll live forever. Here I am alive but lost. –CWS*

## Chronic Pain

*It's so hard to learn how to manage my physical pain. –CK*

Chronic physical pain is one of the most challenging experiences. Those with chronic pain often "look" okay, but inside, their bodies scream with aches, strains, throbbing, and/or burning. They struggle with the persistent impact pain has on daily life. There are days when moving is easier, and other days when each step sends shocks throughout the body. They fight to keep the pain/illness from taking control over their lives.

As a society, we have learned how to support someone experiencing an acute illness but fall short of helping those whose pain extends beyond the short term. There are practitioners, referred to as pain management specialists, who focus on treating chronic pain. Treatments vary depending on the source of the pain and other circumstances. Asking your physician for a recommendation is one way to find such a specialist. Major hospitals have pain management clinics that include physical therapy, occupational therapy, biofeedback, acupuncture, mindfulness, anti-inflammatory treatment (e.g., cryotherapy), and more.

*It upsets me that people tell me what I shouldn't do because of the chronic pain and condition. I hate hearing that I should slow down. –LE*

## Cindy's Journey *Time to Heal*

Today is a beautiful autumn day. Blue sky, colorful leaves, brisk temperature; perfect for a walk. I grab my shoes, but while putting them on, I realize I ache and am too tired to journey out. Sigh. I whine to myself, "I am SO tired of being in pain and tired," but then it hits me. I realize there is a benefit to feeling this way. Feeling pain or fatigue is the body's stop sign. Just like coming to an intersection in the car, pain is our red, octagonal sign with large white letters that reminds us to STOP and evaluate when to go. While I don't like how often I need to stop, I know if I keep moving, I will crash, and rebounding will take even more time. With this moment of clarity, I settle into a comfy chair, open the window, and feel the fresh air. Tomorrow, I might be able to take that walk. Today, I need to heal.

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## 19-Caregivers' Reactions

Medical challenges have a ripple effect. The initial wave knocks the feet out from underneath the patient, but right behind them the undertow tugs at the footing of caregivers and loved ones. As supporters, we try to remain steady, but find that we are peppered by questions and requests for updates. Our thinking is interrupted by thoughts of what we should ask at the next appointment. Sleep is elusive due to our worries. Our lives do not feel like our own as we stay perched to spring into action to help our loved one in their crisis.

In the face of all that transpires, a shift in our feelings is as inevitable as are the changes to our day-to-day routines. When our loved one struggles, it is normal to feel upset about their battles in addition to our own feelings and reactions. Feelings are a sign we are experiencing the reality of the moment. Most of the time, we think of feelings as being something we are overtly aware of, but feelings can sit below the surface, hiding in waiting for a time to emerge. Therefore, not everyone reacts to situations with an increase in feelings or awareness; some experience a decrease in emotions and a flattening of reactions as ways to cope. There is no right or wrong. Reactions are unique to each of us.

In this chapter, we will focus on the caregivers and other loved ones of patients.

- As a primary caregiver and supporter, this information can help you appreciate how your experience influences your emotions and functioning and learn what may be helpful to you.
- The patient will find it helpful to read this to understand what supporters may be experiencing.

## There are No Wrong Reactions

### Shock

*When I first heard about my brother, I was in shock. He had always been so healthy and he was so young.–KL*

Shock is often the first reaction when a sudden and unexplained event occurs. While shock does not feel good, it serves a positive purpose.

Shock is the brain's danger alarm. Shock gets our adrenaline flowing and sends us into action mode. Remember the caveman and the mountain lion? Without experiencing shock, the caveman would quickly be attacked by the mountain lion. Feeling the shock of the moment allows our brains and actions to shift into moving forward.

Once the brain recognizes the danger, as signaled by adrenaline and other neurotransmitters, our brain moves to a second level: a search for understanding. Understanding helps in formulating plans and how to proceed. Creating a plan allows us to be helpful and begin to manage what lies ahead.

*I went into total disbelief, bewilderment, and questioning how did this happen? What caused a very healthy young woman to receive this (appendiceal cancer) diagnosis?–JG*

*I was in shock and didn't really hear what I was being told when my 12-year-old son was diagnosed with leukemia.–LVB*

### Fear, Worry, and Anxiety

*I worry about my son's happiness daily. There is so little he can do and he enjoys far fewer things than he did before. I worry about how or if his life ends before mine. It's hard not to worry when your child can no longer speak. We worry daily about his quality of life and what we can do to enhance it.–RR*

Fear, worry, and anxiety emerge when we, caregivers, are thrust into an unfamiliar world. Our minds are peppered with thoughts of uncertainty. We have no idea how our lives will be from this moment on. Will he die? Will she be dependent on us for the rest of her life? How am I going to cope? What am I supposed to do?

As uncomfortable as anxiety is, it can lead us to be good helpers. Anxiety brings forth “what if” questions, and those “what ifs” drive us to find answers. We can put these worries into the form of questions and present them to medical personnel and others with similar experiences. For example, when Laura’s father-in-law was diagnosed with skin cancer that soon took his life, she worried her husband would get skin cancer, too. It was important for her to talk to the medical team about the genetic component of his particular skin cancer.

### Workbook Chapter 19 Caregivers' Reactions *Worries*

Make a list of your worries and “what ifs.” Turn each item into a question and list whom you can ask to find an answer.

| Worries and What Ifs | Question | Whom Can I Ask |
|---|---|---|
| | | |
| | | |
| | | |
| | | |
| | | |

### Anger and Resentment

*Angry? You bet I’m angry.–BA*

Anger and resentment are often viewed negatively within our culture, but they are appropriate responses to unexpected or undesired situations. It may be hard to pinpoint the specifics of what “creates” your anger, because there is much to be angry about when a loved one is in crisis. Common feelings that feed our sense of anger are how unfair it is, feeling overwhelmed, increased demands upon our time, uncertainty, and vulnerability. Anger can be experienced in three ways: pervasive, directed, and internal.

**Pervasive anger** is an overall feeling of anger that permeates overall mood and reactions. This all-encompassing anger is not directed at any one person, but to many you encounter. Unexpected anger can bubble forth when a colleague makes an unintentional error. Anger can seep out in situations when your typical reaction would not be as explosive or intense, such as water spilling at the dinner table. Difficulty sleeping and having bad dreams occur because the complex feelings of anger surface in our dreams when we are less guarded.

**Directed anger** is focused on a particular person(s) or situation. It is common for us to experience anger at a medical team member who spends less time with us than we need, runs late for our appointment, or brushes off our concerns. We look to medical personnel to solve the problem, and when we see their humanness of being late or unaware of what we need, it causes us to panic. The deep-seated panic turns into anger because it feels safer to be angry than vulnerable in their hands.

Our vulnerabilities and fears sit just beneath the surface, demanding to be heard — and sometimes they are directed at loved ones. Expressing this vulnerability through anger gives us a greater sense of control. After our anger has erupted toward our loved ones, we experience heightened remorse, as we recognize we just added to an already complicated situation.

**Internal anger** is feeling angry but not letting it out. It sits and festers inside of us. Sometimes we don’t even know it’s there. But anger has to go somewhere. If it is not released, it can cause physical maladies, such as high blood pressure, aches, and pains. Releasing anger through physical activity, expressive art, writing, crying, or shouting in the car helps return the body and brain to a steadier state.

Regardless of how anger is expressed, it is important to know it is common. Determine the best way for you to release your anger so your life doesn’t become more complicated.

### Workbook Chapter 19 Caregivers' Reactions *Anger*

List three ways you can release your anger in constructive ways.

____________________________________________________

____________________________________________________

____________________________________________________

*I prayed a lot. Probably fair to say I got angry with God. It was just too much. I still don’t understand it.–LF*

*I ran into a friend who is a doctor and she told me she heard my sister had pancreatic cancer. She made the comment, “Of course, she is doing palliative care.” I didn’t even understand the word “palliative,” but when I looked it up and realized it meant just providing care to keep her comfortable for illness that* *couldn't be cured, I WAS PISSED! I never stopped hoping my sister would get better, so I was really mad at my friend for "giving up." Then one night my brother called me. He told me from the moment he heard she had cancer; he was preparing himself for her death. I was now PISSED at him! How dare he! He was her big brother. I told him she needed us to have hope. He told me I needed to be more realistic. We had a big talk about it and we came to understand we each needed to deal with it our own way. I don't regret not giving up hope. And he doesn't regret spending those four months preparing himself.–AM*

## Denial

*My mother was diagnosed and treated twice in her 30s for breast cancer, but insisted she didn't have cancer. When I was told I had breast cancer, I requested my mother's paperwork from the hospitals where she was treated. When I showed her the paperwork, she finally said, "Oh, I guess I did have cancer." But I still think she never really accepted it.–RG*

Denial is a form of not believing a diagnosis, prognosis, or situation. Denial can be experienced when a situation seems unfathomable. The extreme nature of an accident or illness can cause us to suppress the realization of its seriousness. Both patients and caregivers can be in denial.

Years ago, a couple made a counseling appointment with me. Over the phone, the husband said his wife, Sarah, had pancreatic cancer and was seeking relaxation techniques to help handle the searing pain. I set up the appointment. Sarah, an extremely frail and thin woman, entered my office in a long winter coat on top of sweaters and a scarf. It was August.

Tom laid out the history of Sarah's cancer and treatments. After a few minutes, Sarah asked if she could lie down, as fatigue overwhelmed her. I asked Tom to leave so I could work with Sarah on relaxation techniques.

As the door closed, Sarah told me she didn't want to do anything but sleep. She explained that she knew she was dying. Her doctor told her there was nothing more that could be done, and the second, third and fourth opinions they sought (well, that Tom sought) were all consistent with that. Sarah shared that Tom couldn't accept the reality. "He is denying that I'm dying. He takes me from doctor to doctor hoping to find a cure. I don't want to see any more doctors or have any more appointments. I just want to rest."

Sarah expressing her thoughts and feelings to Tom did not yield any changes. Her words pushed against his denial that his beloved wife was dying. Tom couldn't help it. Experiencing denial was how his brain managed to see Sarah in pain, withering away, and dying. Tom's denial was a protective mechanism that took center stage when feeling and experiencing was just too much.

If you find yourself in denial at times, realize that it is one way your brain is trying to cope. Many times, denial waxes and wanes. A particularly tough day may break down the denial and we realize how worrisome this all is, whereas good days not only give us strength and hope but can lessen our awareness of the impact and seriousness. All reactions serve a purpose.

### Kim's Experience A Brutal Day

Our three-month-old son was in the hospital recovering from having surgery for truncas arteriosus, a rare heart disease. A few days after his second, successful surgery, we were talking to doctors and discussing going home in a few days. Great news.

I noticed he wasn't moving one of his legs. I pointed it out to a nurse, who brought in the neurologist. The neurologist said Matthew had had a stroke. Terrible news.

I was scared. Would he be disabled his whole life? However, the neurologist thought he would recover because he was young. Ok. I need more prayers, but we were still going to be able to bring him home soon. Good news.

Later that morning, the heart team came back in and said they wanted to go back in for additional surgery the next day. Terrible news.

Re-enter the neurology team. I mentioned the additional heart surgery. "No way. He has to heal from the stroke and there can be no surgeries for six months," was the reply. WAIT! Will he die without the heart surgery? I cried when they left.

In comes the heart team, who had spoken with neurology. They had repeated the echocardiogram, and it showed improvement. They wouldn't have to do surgery. We were back to going home in a few days. Good news.

I drove home from the hospital wondering how I was going to be positive for my other two children, five and three years old, who were waiting for me.

It was a brutal day.

## What Caregivers Need to Know

> *We found it incredibly helpful to educate ourselves about schizophrenia and to connect with other people who had loved ones dealing with mental health challenges. Our education included taking NAMI's (National Alliance of Mental Illness) Family-to-Family course. After completing this course, a group of us from the class continues meeting once a month to provide an ear and offer what support we can for each other. We've been meeting once a month for about six years now.–MCM*

Most of us have little knowledge about certain diseases or traumas until we are thrust into the situation. Names of less commonly known diseases, treatment options and medications quickly become as familiar as our own names. We receive an education we never thought we would need.

While many who have dealt with medical crises recommend that caretakers arm themselves with information, not everyone wants to know or learn. Having knowledge about the crisis can lead some to experience increased anxiety, worry, and confusion. Therefore, it is important to know what is important and will help you. As with so much of this journey, the choices are personal and depend on what you need and want.

## Workbook Chapter 19 Caregivers' Reactions *What We Need to Know*

Here's one way to evaluate if you need or want a specific piece of information about your loved one's situation.

### Step 1

| Will this information help me | Yes | No | Maybe |
|---|---|---|---|
| Will it help me be prepared | | | |
| Will it help me understand the diagnosis and treatment | | | |
| Will it help me learn about the course of treatment and what will happen | | | |
| Will it help me understand the side effects of medication, treatment or illness | | | |
| Will it help me be a better advocate | | | |

### Step 2

After you think about the above areas, move to the next layer. Identify what you *want* to know, who to ask for the info, and who will ask. The latter column is helpful if a group of people is working together as caregivers. Together, you can determine who will gather what information and report back.

| | | |
|---|---|---|
| | | |
| | | |
| | | |

### Step 3

A final area is to acknowledge what you don't want to know. Maybe you don't need to know something and don't want to spend time on it. Maybe you don't want to know it now.

What I don't want/need to know

## 20-Mental Health Disorders

> *When Trevor began to experience psychotic breaks, I was confused. I had no idea what was going on, and his behavior frightened me, which was something I had never experienced with him before. Prior to this, he was happy, socially engaged, good student, musician, and athlete. We did not see anything that concerned us prior to his moving into psychosis, which began in his first year in college.–MCM*

> *I wish people close to me would show more concern instead of avoiding talking about our son. –DS*

When we think about medical crises, our thoughts typically imagine injuries or diseases, but another category exists, emotional disorders. Sometimes our loved ones experience emotional challenges throughout life, while for others, there is a sudden onset. Regardless of how long the emotional challenges have occurred, caretakers find themselves mired in the unique challenges of coping with mental health conditions.

When a loved one succumbs to an illness or injury, we tend to stay focused on the moment, but when a loved one struggles with emotional challenges, it spins us into the past. We search our memories. Were there signs that I missed? Was she always like this? Was he depressed and I just didn't see it? Questions bombard us. We think if we can just find an answer, we can make sense out of all of this, and then we will know what to do.

Mental health issues and their complexities create a subset of hurdles. According to the National Alliance of Mental Illness (NAMI), most people with a mental illness have, at some point in their lives, are blamed for their condition. Not only are patients subjected to misunderstanding their supporters are, too. Neighbors and friends don't bring casseroles over when your child is exhausting to manage due to his impulsivity and aggression. Playdates with peers are cancelled when parents learn she has difficulty managing her emotions. We don't tell employers we need to leave early on Thursdays for our family therapy sessions like we would for a dentist appointment. We remain in the shadows, feeling alone and isolated.

Ken offers a look into the complexity of his reactions to his daughter's mental health challenges that took them spinning into a world that cannot be prepared for.

### Ken's Experience *How Did This Happen?*

Our daughter's childhood and adolescence were filled with happy times. She went off to college, but after her first year, she had severe bouts of depression. She expressed a desire to commit suicide along with a sense of hopelessness. I was overwhelmed with sadness, grief, anger, and fear she would kill herself. My mind was filled with questions. How in the world could this happen? What did we do wrong as parents for this to happen? Is this just lack of maturity? How can I fix it? She just needs to snap out of it and grow up. Why can't anyone help her? Why us? Why now? What do I do? How can I help? Where's the beer? This is hard. I want to scream. I can't handle this. I hope that she gets it together. I hope that she stays alive. I feel such profound sadness to see our beautiful daughter, who had no issues growing up, go through such horror. Heartbreaking.

Having a child with any crisis is challenging but I think emotional struggles are particularly challenging because others don't understand them. Cancer is cancer. People understand that, but depression, anxiety, personality disorders, etc., strike at everyone's own vulnerabilities. We shut down. Others don't know how to help.

It has been a number of years since it started. I don't know if my daughter's treatment will ever end. My wife and I sought counseling to work through our thoughts, feelings, and wondering how we could help. We learned that this is her journey and not ours. We wanted to kick her out of the house a few times. Resentment and anger linger. Much of this is still ongoing. We've seen growth and improvement, but it never feels fast enough. A day doesn't go by when I don't think about her and our struggles.

All of this affects my mood. I still feel extreme sadness. I feel guilt. I resent that we were told that she was a "different" child and got "bad parenting" comments, such as, we should have fed her different things or done x, y or z. Unless you go through it, you have no idea.

I try to keep a positive outlook, but it is hard because I don't have any control over outcomes. It is painful to watch. I'm happy about some choices we made and not happy about others. It is like an on-going, massive fire drill. We tried anything that was suggested, hoping it would stick. It takes learning every day. It's hard to push forward and continue doing what I need to do to keep a roof over my family's head and food on the table when running away would be easier.

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## Sarah's Experience *I Wish*

We walked through a revolving door leading us down a path of multiple diagnoses, hospitalizations, medication, psychiatrists, and therapists when our dear son turned 18. The diagnoses landed on Asperger's and schizophrenia; the latter was the harder pill to swallow. Feelings of devastation, confusion, sadness, and uncertainty peppered our nights and days. We just wanted him to be okay.

He never physically lashed out, but would get extremely aggressive, agitated, angry, and moody leaving us scared because we never knew what was going to happen next. Full blown hallucinations and delusions left us confused as to how to help him get through these terrifying times.

Breaking through the mounting flurry of emotions was hurt. Hurt that some family members and friends rejected Michael. They didn't want him to be around, although they never witnessed any of Michael's crises, they just knew the diagnosis and made judgements. They hadn't educated themselves on the syndrome. The stigma of mental illness superseded connections, past history, and love.

My husband and I saw eye-to-eye when making decisions. I can't imagine the double pain of having a partner who saw things differently. NAMI (National Alliance on Mental Illness) was and is a life saver. We attended Family-to-Family classes and support groups with others who were caregivers for a loved one with mental illness. Sharing experiences with those who understood what I was going through was invaluable. They didn't judge. They knew the pain. They understood the journey. Eventually, I cofacilitated the support group which was helpful and gratifying in my journey.

Now, 15 years after the initial schizophrenia diagnosis, Michael lives independently in a condo near where we live. While managing most of his life well, he struggles with maintaining employment. He is punctual, dresses appropriately, works well with children, and is endearing. He has difficulty following directions and tends to wing it, is impulsive at times, and gets misinterpreted. He loves music, playing guitar, percussion, and sitar. His home walls are covered with drawings he has created.

What do I wish? Of course, I wish he didn't have to endure the challenges he has. But, since he has this path, I really wish others would judge him less, be more empathetic, and embrace Michael for the wonderful qualities and talents he has.

## Kate's Experience *Pay It Forward*

I received one of those phone calls that every parent dreads. Our daughter-in-law informed us that our son, Chris, a few hours earlier, took his own life.

There are no words. No one can comprehend the choice that Chris made. What we do know is that alcohol, anxiety, an incredibly stressful year, a gun, and a history of some dark moments, created a tragedy.

Last August, we all had an incredible trip together, sharing laughter, watching our grandchildren bond, and all of us released frustration from this upside world created from Covid, politics, and violence in our country. We never suspected that we would be planning his funeral two months later.

My first reaction was that this is not fair, but unfortunately, I also know that this is all part is life. My faith is carrying me through this. I do believe that whatever Heaven is, that in the end, the spirits and uniqueness of each of us will be there, together to help those still on this earth. I also believe and know that out of every bad thing, good does emerge in ways one would never think of. I received a phone call from a young man, that Chris mentored while he was in AA. He told me with no uncertainty, that Chris saved his life. He is now happily married and has a 3-year-old son. Chris was an organ donor so that also gives us peace. We are also grateful for the 36 years we had with him.

Everyone wants to know what they can do to help us. The obituary mentions NAMI and Chris' son's fund, but really our mantra is to pay it forward in your own way. Paying it forward keeps Chris' memory alive.

## Resources for Emotional Challenges

The American Psychiatric Association has an article on supporting a family member with serious mental illness.[1]

How to help in an emotional crisis according to the American Psychological Association.[2]

NAMI Family-to-Family is a free, 12-session educational program for family and friends of people living with mental illness. It is an evidenced-based program taught by NAMI-trained family members who have been there. Look for a local group.[3]

Mental Health America[4] lists support strategies for parents and other useful information sitewide.

NAMI Family Support Group is a peer-led support group for family members, caregivers, and loved ones of individuals living with mental illness. They are free and confidential.[5]

I Am Not Sick, I Don't Need Help! How to help someone with mental illness accept treatment, by Xavier Amador,[6] gives practical suggestions about how to help someone with mental illness who doesn't believe they're sick.

The Depression and Bipolar Support Alliance[7] has resources for all age groups, including excellent videos with individuals sharing part of their journeys.

The Depression and Bipolar Support Alliance has a network for parents of children with depression or bipolar disorders.[8]

When Your Adult Child Breaks Your Heart: Coping with mental illness, substance abuse, and the problems that tear families apart, by Joel Young and Christine Adamec. [9]

This interview with Ben Affleck discusses the tragedy of addiction.[10]

Alcoholism affects everyone.[11]

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[10] https://www.goodmorningamerica.com/culture/story/ben-affleck-talks-pain-addiction-finding-hope-commitment-69072083
[11] https://www.today.com/video/women-at-betty-ford-center-share-their-struggles-with-alcohol-80461893698

## 21-Your Child in a Medical Crisis

*I vacillated between despair and hope. I put my trust in the highly-esteemed oncologists that they would cure my daughter.–JG*

Most would agree that having a child with a medical crisis and/or chronic health condition is our worst nightmare. Through all the pain and worry about our child, marital relationships can be negatively impacted, making our experiences even more difficult. One study showed that parents who have a child with a chronic health condition more often experience marital dissatisfaction and depressive symptoms than do other couples.[1]

On the other hand, I know of couples who have children with a chronic illness or have died, and the trauma strengthened their relationship. Each one knew that the partner was the only one who truly understood their feelings and experienced.

Being a parent involves multiple roles during a normal day, let alone when our child is in need. Parenting styles vary. Some parents feel compelled to take care of the child, regardless of their age. During this time, the protective parent wants to gather information so decisions can be made. Relationships with our other children, partner, and friends lessen in priority. Work feels like a roadblock to solving and helping. Nothing is more important than making your child well and safe again. Other parents in grief and sadness tend to take a step back, leaning on professionals.

> *During my son's treatment, I tried to think positively and that my son would be cured. I prayed and held onto hope, even when there wasn't any hope.–LVB*

> *[Having a chronically ill or death of a child] creates a loss of all the hopes, dreams, and preconceived anticipations we had for our son.–RR*

The complexity and enormity of having a seriously ill child is conveyed in Robin's journey. Her healthy 3-year-old son started vomiting, and the next day was unable to move.

### Robin's Experience *Mommy, Help Me*

Carter was a full-term, uncomplicated pregnancy. He was fully vaccinated, and until July 31st, 2016, was "typical" for any healthy 3 ½ year old. On Friday, July 29th, Carter vomited after eating pizza. The next morning, he woke up early and wanted water. He chugged his water and I gave him a couple crackers to ensure things would "stay down." Everything was fine and I thought the vomiting was a one and done. I was happy he was staying hydrated and eating some during the day. He fell asleep a little early Saturday and my husband carried him to bed.

The next morning at 8:00 a.m., I woke up to find him on the floor in his room, saying, "Mommy help me, Mommy help me." I scooped him up. He couldn't hold his head up, his right arm was limp at the elbow and shoulder, and his legs seemed a bit weak. We took him to our local pediatric ER. The docs suspected a possible stroke or meningitis. They did a CT, MRI without contrast, and spinal tap. The spinal tap had alarming results and they moved him to the PICU. The lack of movement in his right arm remained unexplained. They started fluids and antibiotics while running other tests to rule out what felt like a million things.

My husband came to stay the night at around 11 p.m., and while Carter still couldn't use his arm, he seemed a bit better. I felt restless all night and got up early to go back to the ER. I walked in at about 6:00 a.m. and watched in horror as a physician and two nurses tried to intubate Carter because he became unresponsive and stopped breathing.

Over the next 48 hours, there were tons of tests. Carter coded twice and we still had no answers; all the while, his ability to respond or move worsened to the point that he had no reflexes anywhere in his body and his eyes were fixed. Unable to wait any longer due to respiratory and pulmonary complications, we went back to the MRI for a full scan on Day 5. We were told our son had something called ADEM: Acute Disseminated Encephalomyelitis, where the body attacks the myelin of its nerves. Nearly 80% of kids make a full recovery.

They started steroids for four days. Little changed. A second MRI of the spine was done. This time it showed damaged gray matter in his brain stem and spine that led to a different diagnosis of Acute Flaccid Myelitis, or AFM. This was significant because not only is it rare, but there is no way to treat or repair it. You only get gray matter as a neonate. There are no drugs, stem cells, or therapies that fix this.

It took multiple MRIs and many days to reach a correct diagnosis. I immediately began second-guessing the hospital I had gone to, the doctors we were working with, and time that may have been unnecessarily lost.

For two years, Carter received what is called "supportive care." These are things that allowed him to sustain life and be as comfortable as possible, given his illness and physical impairments, but nothing that would fix or cure the diagnosis and its domino effect of complications. Supportive care includes physical therapy, occupational therapy, music therapy, and enrollment with a palliative care organization that helped Carter and our entire family with different things.

Throughout these two years, my emotions have been a roller coaster. In the beginning, I was in a mental panic. There is no known cause (etiology) or cure for AFM, and seeing two pages of Google results was extremely disheartening. It was emotionally consuming and numbing all at the same time. I felt hopeless and confused that this seemingly improbable thing was affecting Carter and our family so intensely.

During his hospital stay, sadness, and feeling overwhelmed took center stage. Those feelings were temporarily disrupted by bursts of hope when speaking with other people — physicians, nurses, chaplains and therapists — in the first several weeks. I obsessed on the idea that a solution must be possible. I work in healthcare, and spent hours contacting companies, the NIH, and different physicians to ask about trials that could connect to our son's rare disease.

What happened was beyond basic logic or cause and effect and surpassed anyone's understanding. I questioned every decision and every moment of the days leading up to his sudden onset of symptoms, trying to pinpoint what could have happened. I longed to understand the reasons it happened and how to fix it, believing that if I tried hard enough, there must be a solution.

Medical treatment (all based on empirical evidence) failed. Medications that helped others and months in an out-of-state intense inpatient rehab, which was so terribly hard on the entire family, failed. During rehab, we stumbled on families with the same diagnosis in a private social media group that reported success and improvements. While happy for other families and their kiddos, feelings of resentment and "why us" began. We were working so hard with all the same therapists, facilities, modalities, and specialists, but there was no change. Carter did not improve or "get better" at all. Sadness crept back in in the weeks before rehab discharge, and then grief started — not for death, but for the death of all the hopes, dreams, and pre-conceived ideas or anticipations we had for our son.

The term "new normal" that people uttered was angering. I wanted the old normal. Based on everything I had done and controlled prior to his illness, I felt as a parent I was owed that.

Now, Carter is dependent on a ventilator and not strong or able to care for himself in the least. While trying to make the most of every day, fear lingers from the moment I wake until I close my eyes for a shift for the worse, new complications, or an episode of respiratory distress I won't be able to resolve before EMS arrives. A common cold takes weeks and weeks to clear. I have more monthly insurance fights, therapy appointments, and medical visits than cups of coffee I drink in a month.

I feel like a failure as a Mom and spouse for not taking better care or paying enough attention to my two daughters and husband. I reflect on that failure prior to bed every night, wondering what I missed or what I put off. Sleep and personal coping suffer daily. I question my ability to sustain this journey and wonder what would happen in my absence. The persistence and evolution of feelings is easy to bear when I am immersed in the never-ending list of daily tasks of caring for Carter. That is what I can do to help him.

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*Two years after Carter vomited, he passed away. Carter's mother is an advocate for needed funding and finding a cure for this horrible disease. She lobbied at Capitol Hill alongside senators and physicians, representing her family and others who experience Acute Flaccid Myelitis (AFM). To learn more about AFM and/or to donate, go to https://www.afmanow.org/*

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## What Others Can Do

The illness or loss of a child, regardless of how old the child is, creates anxiety in others because people quickly personalize the situation. When hearing of the illness or death, we, as parents, move to that space, "What if it were my child?" This personalization happens more with the illness or loss of a child than with any other medical crisis. The vulnerability of a child and parent relationship and our desire/need to protect them strikes us at our core.

Much of the time, people don't know what to do for the parents undergoing their child's medical crisis. The MOST important thing to do is to acknowledge what is happening. Ignoring what is occurring and acting as if everything is as usual only makes the family feel isolated.

1. **Practical Help** Offer practical help, for example, carpooling other children, dropping off meals, making lunches for children to take to school, doing their laundry, making a playdate for younger children, inviting children over for dinner, or mowing the grass are some practical ways to assist the family.
2. **Organizing** Thinking through daily needs is exhausting when much of our time is spent caring for our child and managing their care. Therefore, having someone willing to organize weekly needs (e.g., meal train, carpools, care of home) is a significant help.

3. **Create a list** In our culture, we are quick to react when asked how someone can help, as "We're okay" pops out. Therefore, when offering help make a list of what you can do and/or find others to do. Giving your friend a list to check off the items they need reduces the awkward feeling some get when asking for and accepting help.
4. **Help grandparents** Sometimes family members come to help out, particularly grandparents. It is important to help them out too, as they have taken on two roles of supporting their adult child and the grandchildren.

As there are suggestions of what to do, there are suggestions of what not to do.

1. **Don't pepper the parents with questions.** They will share what they want. Offering a listening ear is just that, being a listener.
2. **Don't offer advice** unless specifically asked, and then tread carefully unless you have a specific expertise.
3. **Don't question their decisions**. There is enough uncertainty not to have yours piled onto theirs.

## Resources for Coping with an Ill Child

Robin shared the vast array of emotions that can be experienced when your child is ill. Guilt, responsibility, hope, hopelessness, frustration, anger, and sadness intertwine in a complex mix. Counseling is helpful to sort through the challenges that you face, but I recommend you work with a therapist who specializes in trauma, illness, or the like. These times call for experts who are trained to help in such situations.

The Wonders and Worries website offers important information.[2] Going to the developmental stages tab gives caregivers a deeper understanding of how the child's age impacts their behavior.[3]

Here 4 You is an organization to support parents of medically complex children and offers links to helpful sites.[4]

Band-Aides and Blackboards is a fun, interactive website for kids and teens growing up with medical issues.[5]

The Experience Journals are a collection of stories for children and teens living with physical or emotional illness.[6]

KidsHealth offers online information about child health, behavior, and development for kids and adolescents.[7]

Starbright World® is an online social network for seriously ill teens and their teen-aged siblings.[8]

Parents can learn how to use distraction techniques to help children during medical procedures in Distraction in Action videos.[9]

Healthychildren.org has a good article on dealing with your own feelings.[10]

“How to Help a Child With Chronic Illness: Tips from a child life specialist,” by Andy Kryza, offers practical suggestions on how to manage.[11]

This “Caring for a Seriously Ill Child” article has clear advice on how to talk with a child about their illness, as well as sections about siblings and yourself.[12]

How to Go On Living When Someone You Love Dies, by Therese A. Rando, has a section on dealing with the loss of a parent and other useful information.[13]

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[1] Berge, J. M., Patterson, J. M., & Rueter, M. (2006). Marital satisfaction and mental health of couples with children with chronic health conditions. Families, Systems, & Health, 24(3), 267-285. doi:10.1037/1091-7527.24.3.267
[2] https://www.wondersandworries.org/for-parents/
[3] https://www.wondersandworries.org/child-developmental-stages/
[4] http://www.here4u.net/resources.html
[5] http://www.lehman.cuny.edu/faculty/jfleitas/bandaides/
[6] https://experiencejournal.com/
[7] https://kidshealth.org/en/parents/general/
[8] http://www.tamikothiel.com/starbright/
[9] https://uichildrens.org/distraction-in-action
[10] https://www.healthychildren.org/English/health-issues/conditions/chronic/Pages/Dealing-With-Your-Own-Feelings.aspx
[11] https://www.fatherly.com/parenting/raising-kids-chronic-illness-child-life-specialist/
[12] https://kidshealth.org/en/parents/seriously-ill.html
[13] Rando, T. A. (1991). How to go on living when someone you love dies. New York: Bantam Books.

## 22-Your Sibling in a Medical Crisis

> *I am one of nine children. We were very close throughout our lives, but my brother’s late stages of illness and death changed our family dynamic. It’s as if we all went into our own hole to hide. We walk the walk, but it feels different. Several of my siblings have a lot of anger. They’ve distanced themselves. We haven’t been able to move past this.–CB*

The relationship among siblings is unique in that our siblings have known us throughout most of our lives. We share a common history unlike any other relationship. When a sibling becomes ill, it strikes our core. Being of a similar age to our siblings raises our awareness of our own mortality. Whether the illness is caused by genetic issues, habits, or unexpected events, when our sibling suffers, we feel vulnerable. We cannot escape the thought, "This could have been me."

Just because we are siblings doesn't mean that the illness of a sib will heal past childhood and adulthood differences. In fact, crises tend to accentuate personality traits and styles of coping. This can make unresolved rifts grow deeper, separations wider, and pain sharper. For some, the crisis does create a bridge toward acceptance and forgiveness.

> *It was so hard feeling helpless when all I wanted to do was to support my sister, but she wouldn't let me in. She was withdrawn and maybe in denial.–KBG*

> *The lives of my siblings and mine changed. The summer our brother was diagnosed, we went to a patient/family seminar sponsored by the International Myeloma Foundation. I found out about it and got us enrolled. My sister, who is a nurse, went with Paul to his doctors' appointments. My other sister helped him with paying bills and fighting with insurance companies. We had to watch we didn't overwhelm Paul and only give him the information he asked for.–KL*

> *By far the hardest aspect of my brother's illness and death was the feeling of helplessness.–CB*

Siblings often walk through life by our side. When a sibling is struck by a medical crisis, it shakes our foundation, as seen in Aileen's journey with her sister, Ellyn.

### **Aileen's Experience** ***I Wear Purple***

The stomach pains my sister Ellyn was having were diagnosed as Stage IV pancreatic cancer. She was 54 and I was 41. I refused to let my mind go to where we were headed. I took up mindfulness training with her, convinced it would make the cancer go away. I wore purple (the color of pancreatic cancer) every day. I stayed optimistic. I encouraged her and other family members. I got very involved in the Pancreatic Cancer Action Network and did a lot of research. I looked into medical trials and talked to my sister a bit about them. She thought about going to Mexico for some kind of treatment, Hopkins or MD

Anderson, but she felt very comfortable with her care and didn't want to leave her home. Her husband is a doctor and is on staff at a major university medical center in the Midwest, so she was getting great physical care, but also a lot of TLC because everyone at the hospital knew them. To this day, I wonder if she would have had more time had she gone to one of those places to be part of some kind of medical trial.

From the second Ellyn got the diagnosis, her only concern was leaving her kids, especially Caroline, who was her youngest at 17 and a bit of a "free spirit."

Four short months after the diagnosis, her doctors said there was nothing more they could do except offer her palliative care. The day they received that news, her daughter, Caroline, went to her church youth group to help her cope with the impending loss of her mother. After the youth group, she decided to go see my sister in the hospital. On the way to see her mom, Caroline was killed in a freak car accident.

While we were all trying to prepare for my sister's approaching death, we suddenly had to deal with the horrific loss of her youngest daughter.

After the accident, they brought Caroline's body to the same hospital Ellyn was in. Ellyn and her husband went down to the morgue with one of my other sisters and a close family friend who is a doctor at that hospital. My sister said Ellyn touched Caroline and said, "I knew this kid couldn't live without me." Ellyn was so sad, but honestly, the full impact of Caroline's death affected her differently than most mothers in that situation, because of the medications she was on due to the cancer they added other medications to help her cope with Caroline's death.

Two days later, Ellyn's son and I were with her in her hospital room, talking about plans for Caroline's funeral. Her son was telling her about people who were coming from out of town to attend the services. She looked at him and just said, "Don't they know they will have to come back in two weeks?" Ellyn died nine days later.

Ellyn was hell-bent on making it to Caroline's funeral. Her oncologist visited the church with a nurse a day or two before with an ambulance crew to decide where they would all sit and what they would do if Ellyn needed immediate care during the service. She was so very weak. The morning of the service, I was at the hospital with her. She had been trying to do some standing every day with the help of one of us and the nurses. She could barely stand, and when I left the hospital to pick up someone at the airport for the service, I was convinced she would die while I was gone. She was so sick with the cancer I do not believe Caroline's death was fully sinking in.

Ellyn gathered her strength and made it to the service. She was brought by an ambulance and came down the aisle in a wheelchair. She stood with a lot of help and sat in a pew. She smiled a lot at the service, while tears rolled down her face. When it was over, the nurse and her husband started to get her back into her wheelchair. She refused; she wanted to walk out of the church. She did, with her husband on one side and her two other children on the other. She had a smile on her face. She waved to people and thanked them for coming. It is my belief she was glad she would be with Caroline, or better said, that Caroline would be with her.

The compound loss of Ellyn and Caroline is incomprehensible even now. With my brother-in-law's blessing, Caroline's volleyball coach wrote a book that was made into a movie. While we are all a bit worried about such a painful point in our lives being so public, we do believe Ellyn and Caroline's story is special and can inspire others. I can't even begin to enumerate all the ways this tragedy positively affected us and literally thousands and thousands of others. The movie is called The Miracle Season.[1]

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## Resources for the Death or Illness of a Sibling

Although written for teens, Erica Hyatt's book applies to adults as well: Grieving for the Sibling You Lost. [2]

Surviving the Death of a Sibling: Living through grief when an adult brother or sister dies, by T.J. Wray.[3]

Healing the Adult Sibling's Grieving Heart, by Alan D. Wolfelt.[4]

The Center for Life and Loss Transition has an article, "Helping Yourself Heal When an Adult Sibling Dies," by Alan D. Wolfelt, Ph.D.[5]

How To Go On Living When Someone You Love Dies, by Therese A. Rando,[6] has a section on dealing with the loss of a sibling, as well as other useful information.

Sober Siblings: How to help your alcoholic brother or sister and not lose yourself, by Patricia Olsen and Petros Levounis, M.D.[7]

"Caring for Siblings of Seriously Ill Children"[8]

"When a Sibling Is Seriously Ill"[9]

In the Shadow of Illness, by Myra Bluebond-Lang, is a book for parents and siblings of a chronically ill child.[10]

Hi, My Name is Jack, by Christina Beall-Sullivan, is a book for young children about a sibling who is in and out of the hospital.[11]

A list of resources containing specific recommendations for siblings with specific illnesses or disorders.[12]

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[1] https://www.youtube.com/watch?v=bAHAwesTLB4
[2] Goldblatt-Hyatt, E. (2015). Grieving for the sibling you lost: A teen's guide to coping with grief and finding meaning after loss. Oakland, CA: New Harbinger Publications.
[3] Wray, T. J. (2003). Surviving the death of a sibling: Living through grief when an adult brother or sister dies. New York: Three Rivers Press.
[4] Wolfelt, A. D. (2008). Healing the adult sibling's grieving heart. Independent Publishing Group.
[5] https://www.centerforloss.com/2016/12/helping-heal-adult-sibling-dies/
[6] Rando, T. A. (1991). How to go on living when someone you love dies. New York: Bantam Books.
[7] Olsen, P., & Levounis, P. (2008). Sober siblings: How to help your alcoholic brother or sister--and not lose yourself. Cambridge, MA: Da Capo Lifelong.
[8] https://kidshealth.org/en/parents/sibling-care.html
[9] https://kidshealth.org/en/teens/ill-sibling.html
[10] Bluebond-Langner, M. (1996). In the shadow of illness: Parents and siblings of the chronically ill child. Princeton, NJ: Princeton University Press.
[11] Beall-Sullivan, C. (2010). Hi, my name is Jack (a book for the healthy siblings of chronically ill children). Park City, UT: Beall-Sullivan.
[12] https://www.chadkids.org/child-life/child-life-recommended-books.html

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## 23-Your Friend in a Medical Crisis

*My heart broke as I heard the news that his cancer was back. His active lifestyle was halting once again. Will this be the last resurgence of the cancer?-DS*

### Leigh's Experience *I Wanted to Fix Her*

Five months after her treatment, she was diagnosed with a different type of breast cancer, and it was Stage 4. She had a mastectomy and more; in the doctor's words, "We threw the book at her." She fought harder than I ever thought possible. When she knew she was going to die, she started to withdraw. I am crying as I share this because watching her suffer and slip away broke my heart. I wanted to fix her, take away her pain and suffering, and give her young life many more years to live. Becky died at age 46, six months after her PET scan. I really miss my sweet friend more than anyone will ever know.

Friends are impacted when someone they care about is experiencing a medical crisis.  Often they want to help but may not know how. It is important for us, as friends, to put our needs well below the friend's and family's.

### **Roger's Experience** ***Go Away***

Living and dealing with a spouse undergoing chemotherapy was the most difficult experience of my life. It tested every aspect of me as a person, husband, and friend. I became a caregiver, confidant, and cheerleader.

My wife was undergoing dose-dense chemotherapy, which basically left her immobile on the couch every other week. I had to assume a role that I never expected. My wife did not want to see or even talk to friends. It was just too exhausting for her. But many people did not understand this, and I had to become a gatekeeper to monitor calls and attempted visits.

One friend was relentless in her desire to see my wife. When the doorbell rang and I opened the door, she handed me a package and inquired how she was doing. I told her she was having a particularly rough day, as her chemo session had been two days ago and it took about 48 hours to really have its effect. She asked me if she could see her. I politely told her no, that my wife was in too much pain, but I appreciated her kindness and would convey her feelings to my wife. Just then, our phone rang, and my wife weakly answered it, as I was at the door. The “visitor” heard her answer the phone, pushed me out of the way, and walked into our house, boldly announcing, “Of course she will see me.” I still feel angry that she was so self-centered and that the wishes and needs of my wife were disregarded, particularly by someone who was supposed to be her friend.

## Resources for When Your Friend is Ill

Life Saving Friendships: Helping A Friend Cope With Illness, Death & Dying is a Kindle book by Julie Keating[1]

When Life Becomes Precious: The essential guide for patients, loved ones, and friends of those facing serious illnesses, by Elise NeeDell Babcock[2]

Beyond Casseroles: 505 ways to encourage a chronically ill friend (Conquering the confusions of chronic illness), by Lisa J. Copen[3]

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[1] https://www.amazon.com/Life-Saving-Friendships-Helping-Illness-ebook/dp/B00JI774R8
[2] Babcock, E. N. (2002). When life becomes precious: The essential guide for patients, loved ones, and friends of those facing serious illnesses. New York: Bantam.
[3] Copen, L. J. (2008). Beyond casseroles: 505 ways to encourage a chronically ill friend. San Diego, CA: RMP, Rest Ministries.

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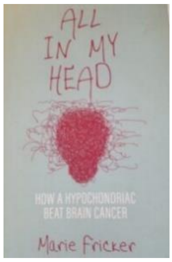
## 24-Your Spouse/Partner in a Medical Crisis

> *I wish more people had been aware of my husband's suffering and offered him support too.–JN*

The role of a spouse/partner is made more complex when a medical crisis strikes. Spouses/partners are often the primary caretakers, followed by adult children, close friends, and paid staff. The primary caretaker becomes the leader in the fight for wellness. This demands time. Time to make appointments, handle insurance, fill others in on what is occurring, and take on more responsibilities at home. Leisure activities, work, holidays, and other family members take a back seat to the illness.

Emotional reactions run the gamut among partners. The partner's reactions do not significantly differ from the experiences felt by patients; the closeness of the relationship heightens responses and fears. How each of us responds in these situations varies depending upon a number of factors, such as age, gender, financial impact, prognosis, and personality.



Identifying the way you usually respond to stress can help you assess how you are likely to respond to the current situation. For example, if you tend to respond to stress by finding information about a situation, you are likely to research the symptoms, treatments, surgery and the like that could fit your partner's situation. If you are inclined to avoid uncomfortable situations, you might close yourself off from the events around you, as it can become too distressing for you. Marie Fricker wrote a book, All in My Head: How a Hypochondriac Beat Brain Cancer, about her brain cancer. She has an amazing way of sharing pain, angst, and real-life experiences through description and humor. Yes, I said humor. In her book, she reveals how her husband, who tends to avoid emotions, handled part of her journey.

My husband Al has never been diagnosed with a life-threatening disease, but if he were, I know he would survive. His life is a carefully scheduled routine from which he never wavers… My brain tumor was not part of Al Fricker's neatly ordered routine. At first, he was completely in denial, believing that this disastrous turn of events had never really occurred. Then when he realized it was true, Al decided that he could continue his normal sixty-hour work schedule, and I would be all right with the help of others in my life.[1]

The story unfolds with Al negatively reacting to Marie's request to launder a load of pajamas for her. His reaction is brought up short by their adult daughter, who chastises him. Their daughter's reaction jolts him to move to a different response style. He offers a sincere apology, along with some tears, and the incident shifts him to being more helpful.

Is Al likely to shift back into his "life as normal" stance? Yes. We are who we are based upon a lifetime of learning and habits — but developing newer ways to handle the enormity of a medical crisis expands us in ways we might otherwise never experience.

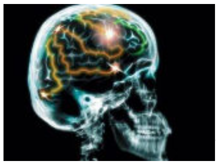
*I began to feel separate from the rest of the world, as if we were in a different universe. I felt envious of other couples who seemed to be contentedly going about their everyday tasks without a care in the world.–SH*

*Once the diagnosis of glioblastoma (a deadly brain tumor) was confirmed, I became focused on how to get the best post-operative care to keep my wife as comfortable as possible. During this time, my emotions were more constrained than normal (they are typically very constrained) as I focused on fighting for her day-to-day.–KH*

*Suddenly, I was the sole financial and decision-maker for our family.–NL*

Through the bond of committed relationships, we create a shared vision. Vince shares how the vision he and his wife had for life was shattered.

### Vince's Experience *This Was My Wife*



When my wife began showing signs of abnormal behavior, I never imagined the emotional and financial impact her care and treatment would have on me. For several months, we struggled to find a definitive diagnosis. As we struggled, her condition continued to decline. Finally, after three days of neuropsychological testing, an MRI, and a PET scan, she was diagnosed with frontotemporal dementia (FTD). This disease has several effects, and all are unpleasant.

Debby lost the ability to speak and eventually could not even communicate by nodding her head "yes" or "no." FTD robs its victims of the ability to feel or display emotion. Debby's facial expressions don't change. But the symptom of severe agitation that accompanies FTD drove my decision to place her in a memory care facility. Four physicians advised me to find residential memory care for her as soon as possible. They explained that if she became severely agitated before being admitted to a facility, no place would take her. However, if the agitation arose after she was a resident, the facility would have to continue to care for her. [Debby on left. Disconnected to what was happening was part of her progressive FTD.]

I began a frantic search to find the right care facility for her. It was a frantic search because facilities with locked memory care units are scarce; they have few openings; long waiting lists; and are expensive. I felt fortunate because I had a personal connection with a nearby facility, and both Debby and I have long-term care insurance. My connections worked, and within two months, Debby was in a wonderful place just eight miles from home.

Of course, the people in charge did their due diligence and required financial statements, tax returns, verification of insurance, and other information to ensure I could afford to pay for Debby's care. We passed the screening. It took weeks and massive amounts of patience to complete the insurance company's required paperwork and get their approval. Finally, after jumping through a multitude of hoops, the nerve-wracking struggle seemed to be over, and Debby entered a facility that was better than I could have hoped for. I bought a bed for her room, curtains, furniture, a television, etc., and with help from some very good friends, moved her in. I took pictures of Debby's nicely decorated room and sent them out to family and concerned friends to reassure them that Debby was well cared for.

However, I had made one very big mistake. I'd assumed the long-term health insurance would cover the complete cost of her care, and the facility would provide a bill and the insurance company would pay it. After all, she had nearly $400,000 of coverage. However, it doesn't work that way. The actuaries and accountants — I suppose using formulas that consider life expectancy, age, and the amount of coverage available — calculate and provide only a portion of the monthly expenses for care and services. Debby's insurance provides just over $6,800 a month. However, the cost of care and services in the place she was now living in turned out to be well over $9,000. The daily rate was $317, and the additional cost, which depended on the level of care required, would over time increase the monthly cost to well over $10,000.

Then the bill for the first seven weeks of care arrived, and I discovered that in addition to the $6,800 the LTC (long-term care) insurance provided, I had to produce an additional $8,000 (thank God for retirement saving plans). I was able to pay for those first seven weeks of care, but I could not afford the additional $3,000-4,000 each month that the LTC (long-term care) insurance didn't cover. I was both devastated and embarrassed. How could I have so completely misunderstood the LTC insurance terms? My only explanation was that we'd purchased our policies about 17 years earlier, and I'd forgotten that critical detail.

For several months, perhaps more than a year, my life had been completely unsettled — doctors' appointments, paperwork, phone call after phone call to the insurance company, trying to care for Debby on my own, the stress of finding somewhere to place her, repeatedly second-guessing myself, calculating the finances, and so much more. Now that Debby was receiving good care, I believed things were at last beginning to stabilize and calm down. Suddenly, that stability went up in smoke. I had to start all over again to find a facility I could afford that also had an opening. Among the handful of dementia care facilities in the state, the closest one was 45 miles away from home; anywhere else was 75 or more miles away. After a couple of weeks, the closest facility called and said they had an opening. I did the paperwork, financials, and insurance forms again. Then finally, sadly, we packed Debby up and moved her to the new place. Fortunately (I suppose), she didn't appear to either recognize or be disturbed by the change.

This new facility was more affordable and if the first one was an “A”, this one is a “B+”— a wholly acceptable difference despite the distance from home. The daily fee at the new place is $270 and there is no up-charge for increasing levels of care. They are directly connected to hospice, and there is no additional charge for that service either. I still have to pay about $1,300 each month to cover what the LTC insurance doesn’t, but that’s an amount I can cover. Stability seems to have returned to my life. Most important, Debby is well cared for.

It’s difficult for me to describe the emotional turmoil I experienced throughout this long process. Everyone has had to deal with seemingly impenetrable bureaucracies at one time or another, but this time it was different for me. I wasn’t trying to get my phone bill straight or deal with a cable provider. This was my wife of nearly 35 years, the woman I loved. As she was falling apart, I seemed to be, too — the empty house, all the chores and daily tasks that we’d shared were now all on me. I had to deal with the trauma of losing Debby in every sense except for the fact that the body she once inhabited is still present. [Picture of Debby and Vince during a happy, healthy moments never knowing what was in store down the road.]

People close to me have often said they don’t know how I’ve managed all of it, and I only have one answer: “What else could I do?” I couldn’t run away or hand my problems to someone else. It might sound boastful, but I knew I had to put my head down and keep pushing and pushing. I couldn’t allow my emotional stress to interfere. I must say that I didn’t do, and couldn’t have done, this by myself. I had tremendous support from family and good friends and from the many people who loved and cared about a uniquely wonderful woman, my Debby.

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## Resources for When Your Partner Is Ill

This research study on the impact of living with a spouse with a chronic illness includes a list of more research that includes specific topics, such as multiple sclerosis, Parkinson’s, and more.[2]

“Your Spouse Has a Chronic Illness: Here Are Ways of Coping,” by Sheri Stritof.[3]

How to Be Sick: A Buddhist-Inspired Guide for the Chronically Ill and Their Caregivers, by Toni Bernhard.[4]

An easy-to-read article from Psychology Today: “Turning Straw Into Gold: A Not-To-Do List For Caregivers of the Chronically Ill,” by Toni Bernhard, J.D.[5]

The Caregiving Wife's Handbook: Caring for Your Seriously Ill Husband, Caring for Yourself, by Diana B. Denholm[6]

Mental Illness and Your Marriage, by Jim Stout & Leah Stout[7]

Dancing with Elephants: Mindfulness Training For Those Living With Dementia, Chronic Illness or an Aging Brain, by Jarem Sawatsky[8]

“Spousal Caregivers: When chronic illness crashes into your marriage,” by Todd Foley.[9]

“How to Keep Your Marriage Healthy When One of You Is in Pain,” by  Suzanne Levy[10]

Let's Talk Dementia: A Caregiver's Guide, by Carol Howell[11]

How To Go On Living When Someone You Love Dies, by Therese A. Rando has a section on dealing with the loss of a spouse/partner, as well as other useful information.[12]

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[1] Fricker, M. (2017). All in my head: How a hypochondriac beat brain cancer. Mustang, Oklahoma: Tate Pub & Enterprises, p. 77.
[2] Eriksson, E., Wejåker, M., Danhard, A. et al. “Living with a spouse with chronic illness – the challenge of balancing demands and resources.” BMC Public Health 19, 422 (2019). https://doi.org/10.1186/s12889-019-6800-7
[3] https://www.liveabout.com/cope-when-spouse-has-chronic-illness-2302978
[4] Bernhard, T., & Boorstein, S. (2010). How to Be Sick: A Buddhist-inspired guide for the chronically ill and their caregivers (1st ed.). Somerville, MA: Wisdom Publications.
[5] https://www.psychologytoday.com/us/blog/turning-straw-gold/201401/not-do-list-caregivers-the-chronically-ill
[6] Denholm, D. B. (2013). The caregiving wife's handbook: Caring for your seriously ill husband, caring for yourself. Alameda, CA: Hunter House.
[7] Stout, Jim, & Leah Stout (2017). Mental Illness and Your Marriage. San Antonio, Texas: Shepherd Publishing
[8] Sawatsky, J. (2017). Dancing with elephants: Mindfulness training for those living with dementia, chronic illness, or an aging brain. Manitoba: Red Canoe

Press.
[9] https://www.focusonthefamily.ca/content/spousal-caregivers-when-chronic-illness-crashes-into-your-marriage
[10] https://www.health.com/condition/pain/how-to-keep-your-marriage-healthy-when-one-of-you-is-in-pain
[11] Howell, C. L. (2015). Let's talk dementia: A caregiver's guide. Pittsburgh, PA: Hartline Literary Agency.
[12] Rando, T. A. (1991). How to go on living when someone you love dies. New York: Bantam Books.

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## 25-Your Parent in a Medical Crisis

*When we learned my mom had Stage 4 cancer, my Type A personality went into overdrive. I was "her person" full-time. I took care of all medical documentation, appointments, and care (along with assisted living personnel) and coordinated with hospice. I did this because she was "my person" growing up. I was just paying her back for all that she had given to me over the years.–AR*

Relationships with parents typically have ups and downs. We might cling to our parent at five years old, only to push them away as teens as we strive for independence. Through all of our experiences, we hope to have parents who can provide guidance, support, and ultimately, friendship. Some of us will find that perfect balance; others will not. The absence, tension, or turmoil that characterized our parent-child relationship can continue throughout adulthood.

Regardless of how our relationship unfolds, when a parent enters a medical crisis, the trends in our relationship are heightened. If we have an overall positive relationship with a parent, that pattern tends to persist. If the parent/child relationship has been less rewarding, there can be a resurgence in the feeling of regret that the relationship isn't more of what we wanted. In either situation, a sense of loss is felt. We no longer have the parent who taught us how to ride a bike, made the worst meatloaf, called us by our sibling's name, waited for us to come home, or forgot to call us on our birthday.

*It may seem odd, but I learned a lot being with my mother when she was dying. We talked, but not much about how she felt, what kind of service she wanted, or other end of life topics. As I think back on it, not only do I know what I wish I had done differently, but I've also learned what I want to happen if I am in the same position as my mom.–GT*

*I have a hard time going to church these days. The music is what my mother loved the most and it just hits me in the heart — every time.–AR*

*I was one during my mother's first breast cancer diagnosis, which resulted in a radical mastectomy. When I was five, cancer was diagnosed in her other breast, and again, she had a radical mastectomy. All I can remember is that she wasn't home a lot, and we had family and neighbors taking care of my brother and me. She and my father divorced shortly following the second diagnosis. This had an additional negative impact on my emotional well-being as a child. I was a very sad and depressed child.–RG*

*My father passed away 21 years ago, and I still wait for his Sunday phone call. Some memories are meant to stay forever.–CWS*

*I was scared when my mom was diagnosed with cancer. Having lost my father at the age of eight, the idea of being without any living parent was completely overwhelming. I had just gotten engaged, so thoughts of whether my mom would make it to my wedding, see her grandchildren, etc., all regularly went through my head.–KW*

Experiencing a parent's illness can leave us feeling unmoored. Lisa and her mother were exceptionally close to one another, and their journey illustrates the bond and impact.

### Lisa's Experience *Torn Black Ribbon*

My mother was actively dying from metastatic breast cancer that had been diagnosed 12 years earlier. I was not only one of my mother's primary caregivers in her final months, but we were unusually close, and during that time she came to rely on me a great deal, from medication management to backrubs, handholding, and telling her the truths of her condition. I'd been able to focus keenly on her needs and comfort, and it was the great honor of my life to be connected so completely with Mom at such a sacred time.

Six weeks before my mom died, I was diagnosed with breast cancer, the same disease that was killing my mom. Upon being told the diagnosis, I became disoriented, fuzzy, and furious that the spell of closeness between us had been broken at the time she needed me most.

I briefly considered not telling her about my diagnosis and explored the pros and cons — or rather the cons and worse cons — with family and friends. In the end, I decided to tell her for several reasons. First, I was one of her primary caregivers and didn't know how I'd explain my sudden disappearance and re-emergence with a flat chest and drainage tubes. Also, we were exceptionally close, and she knew me completely. She would detect that I was stressed and hiding something, which would distress her in turn. My friend, Leslie, said it best. "Would you want to know if Brian (my son) was sick, even if you were on your deathbed?" The answer was yes, and I steeled myself for the hardest conversation of my life. My husband and I went to my parents' condo. We sat in the dining room and I told my parents. My mother's face became anguished. She couldn't speak. I don't remember my father's reaction. I think he was crying. But it was my mother's expression of torment that haunts me to this day, and I believe that my disclosure hastened her death.

I was in the rather unique situation of being able to talk with my Mom about my breast cancer as she was about to lose the battle of her own. This was exquisitely painful in so many ways. However, my mother was an extremely positive person and nurturing parent. She wanted to help me, and she did, even as she was dying. We would sit together, talking and holding hands in a sacred and intimate space much like the one we'd shared throughout our relationship — just sadder and more profound in its irony. One day, we were talking about reconstruction. I told Mom what I'd heard from my doctor about the total loss of sensation that typically accompanies mastectomy, and I asked her if it were true. She'd had natural reconstruction, and mine would be done with silicone implants, but I thought our experiences might still be comparable. Mom, who was weakening daily by this point, told me yes, but that I shouldn't worry because it really wasn't so bad. And in fact, that throughout her cancer, she'd found that with each new challenge, there was always something good that followed. I looked at her incredulously. "Something good?" I exclaimed. "How can a total loss of breast sensation have anything that's good?" With a faint smile and a gleam in her eye, she pointed downward, saying, "Because the sensation moves south." I was the social worker, but Mom knew how to make people feel better, no matter what. Though she didn't survive for me to tell her, she was in fact correct.

I went into surgery with a torn black ribbon pinned to my gown for my mother, who died seven days before.

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In psychology, there is a concept referred to as Rosy Retrospection.  Rosy retrospection is shading the memory of the person who passed away as only good and not recognizing the flaws in the relationship or person. By having rosy retrospection, it helps some people cope with the loss and unresolved challenges in the relationship. For others, recognizing the shades of the relationship and person feels authentic and thus they are able to move on.

Susan’s experience with her father illustrates how a complicated relationship with a parent doesn’t change just because he is ill or dies.

### Susan's Experience *The Good Daughter*

Dad and I always had a rocky relationship. He wasn’t emotionally equipped to keep me safe as a little kid. Bad things happened, and a wedge of distrust was forever inserted between us. As an adult, I did my best to remove the wedge, to be the good daughter. We projected the public appearance of a happy, loving relationship, but I never actually felt it. I don’t believe that he did either. When I finally shared with close friends who saw us together every week at our place of worship, they were shocked to learn that I didn’t actually love or trust Dad.

Keeping up the appearance that everything was fine was exhausting and it became unbearable when Dad’s life began to descend into chaos, taking mine along with it. He made reckless choices and involved himself with dangerous people. Even with the help of family, friends, clergy, counselors, and law enforcement, I/we couldn’t change the horrific path of his life.

To protect myself and my loved ones from potential violence, I made the difficult choice to end my relationship with Dad. He died three years later.

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### Resources for When Your Parent is Ill

The Emotional Survival Guide for Caregivers: Looking after yourself and your family while helping an aging parent, by Barry Jacobs, Psy.D.[1]

Dancing with Elephants: Mindfulness training for those living with dementia, chronic illness or an aging brain, by Jarem Sawatsky[2]

Lindsay Lyon summarizes the work of journalist and author Francine Russo in “Nine Mistakes Adult Siblings Make When Parents Are Aging, Sick, and Dying.”[3]

How To Go On Living When Someone You Love Dies, by Therese A. Rando, has a section on dealing with the loss of a parent, as well as other useful information.[4]

Dying Well with Hospice: A Compassionate Guide to End of Life Care, by Paula Wrenn & Jo Gustely, RN[5]

Let's Talk Dementia: A caregiver's guide, by Carol Howell[6]

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[1] Jacobs, B. J. (2006). The emotional survival guide for caregivers looking after yourself and your family while helping an aging parent. New York: Guilford Press.
[2] Sawatsky, J. (2017). Dancing with elephants: Mindfulness training for those living with dementia, chronic illness, or an aging brain. Manitoba: Red Canoe Press.
[3] https://health.usnews.com/health-news/family-health/boomer-health/articles/2010/01/28/9-mistakes-adult-siblings-make-when-parents-are-aging-sick-and-dying
[4] Rando, T. A. (1991). How to go on living when someone you love dies. New York: Bantam Books.
[5] Wrenn, P., & Gustely, J. (2017). Dying well with hospice: A compassionate guide to end of life care. Place of publication not identified: Amans Vitae Press.
[6] Howell, C. L. (2015). Let's talk dementia: A caregiver's guide. Pittsburgh, PA: Hartline Literary Agency.

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## 26-We Weren’t Expecting these Reactions

Some side effects are predicted by medical teams, while others are not. Patients bring personalities, physical sensitivities, strengths, and weaknesses that impact their reactions to challenges, medication, pain, and treatment. While we, caregivers, twist and turn to adjust to their side effects, we are sent down a rabbit hole of our own.

Many of us find ourselves in a position of helping our loved one agree to receive interventions with the goals of healing and helping. Our positive intentions can be shoved aside and replaced by guilt when we see side effects ravage a person’s personality, reactions, and well-being. We question whether we should have encouraged him to go down this course of treatment. We worry that she may never be like her old self. We ache as he gasps in pain. Doubt clouds our thoughts and we wonder if we said the right thing. The turmoil churns within, yet we stoically remain positive not wanting our own uncertainty to be seen.

### Who is This Person?

> *My mom turned into someone I didn’t recognize. She acted strange and did odd things. We didn’t know if it was from the cancer, or from not taking her*

*antidepressants and anxiety medication, or if it was the methadone and morphine she was taking.–RG*

Illnesses, side effects, and medication, as well as personality, affect how the patient reacts to what they are experiencing. These aspects, on top of the roles we have with the patient, complicate our feelings and reactions.

Our loved ones' reactions can change our relationship with them. A colleague shared that she feels so embarrassed when her mom, who has dementia, acts confrontational, insensitive, and abrupt with the staff who care for her. "I cringe at the way she barks orders, calls the aides stupid, and complains. I worry that the staff will not care for her as carefully because she is so difficult. I probably go overboard, but once a month I bring lunch in for the staff, hoping my appreciation will mitigate the impact of my mom's behavior."

*My son is a good person, but when he experiences paranoid delusional thinking, I'm afraid he might hurt me.–MCM*

*My mom was not the ideal patient. When things didn't go as explained (for example, at first she was told she didn't need radiation, but then she did) she would get angry and argumentative. Dealing with losing her hair, getting sick from the chemo, her nails turning black, her appetite changing were all very difficult. She gained a crazy amount of weight from the steroids they would pump into her two days before each chemo treatment. We just had to remain positive and maintain the take-charge attitude so that she wouldn't feel defeated.–KW*

### Kathy's Experience *I'm Not Taking This Anymore*

The hardest part for me was when my brother would get angry. He knew he could take it out on us and we'd still be there for him. Lord knows he had a right to be angry at the disruption and total change to his life and the ultimate knowledge that his life was going to be cut short. However, it was hard to take sometimes when we felt like we had been doing a lot for him. One time, he chewed me out on the phone. I thought, "I am not taking this anymore," and gave it right back to him. He hung up on me and then called me back later to say he was sorry. He had just found out he was out of remission again. I felt about two inches tall. I realized it was important to have time to vent feelings away from him. It was so dark and depressing.

## You Know Them Best

It's important to realize that you have information about your loved one the medical team does not. If you observe changes in personality and reactions, it is likely that the medical team isn't aware they are acting differently from their usual demeanor. Therefore, it is important to share what you are observing so the team can incorporate this information into their understanding and make needed recommendations. Remember, you know your loved one best.

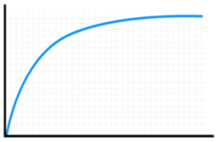
## Medication Side Effects

Have you seen medication commercials that promise to help with a condition, and then a long list of possible negative reactions fills the screen? Possible side effects run the gamut from slight nausea to seizures and death. There's always a disclaimer at the end that indicates such side effects are rare — but how can we know if our loved one will be affected? When deciding what to do, most of us follow the medical team's advice and get the needed prescriptions filled.

> *My wife was on high doses of steroids during some of her treatment. I could tell which day of the week it was by her reactions. The steroids were administered on Wednesdays, so Thursday through Sunday were punctuated by her heightened reactions, weepiness, and anxiety. As Monday rolled around, her mood settled back to her usual self, only to swing to extremes again on Thursday, week after week.–BS*

Michele's experience illustrates how we can be taken by surprise by the side effects a loved one can encounter.

## Michele's Experience *A Learning Curve*



When preparing to take care of my husband after back surgery, I never gave a second thought to the medications he would use to "get ahead of the pain," enabling healing to occur. What I soon came to find out was that the side effects of them had a major impact on my delivery of caretaking. My husband, who is normally an active, intelligent, clear thinking, independent and positive person, became confused, dazed, lethargic, and prone to anxiety and imagined fears. This experience was frightening, confusing, and new to me. There were many times when he experienced hallucinations.

(Husband) “I had a terrible night last night. I spent the night crawling around on the floor trying to get away from the people who were trying to get into our house. Didn’t you hear them? I closed the bedroom door and tried to lock it, but I couldn’t figure out how.”

Being the caretaker 24/7 took its toll. What helped me through the process were periodic visits from family members who would relieve me, allowing me to get out, do errands, and just clear my head. That was crucial. It was a huge learning curve.

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If you observe unexpected reactions from medication, it is essential to let the prescribing doctor know. Underscore that the behaviors and reactions you are seeing are different from how he usually handles medication and/or situations. You should receive an explanation from the physician as to why the change is happening. The doctor may also adjust the medication dosage or change the actual medication to lessen the negative side effects.

## It’s Their Decision

*I didn’t want my mother to suffer unnecessarily at the end of her life. I think it’s important to give people their own choices if they are mentally capable. I hope I can carry this through as my husband and I age.–MR*

Some of us, having the best intentions, want to make decisions for our loved one. We want to make decisions we think will help the person heal and feel better. However, it is not our decision to make. As long as the patient is able (and an adult), it is their decision to make. They need a sense of control in an out-of-control situation in which their bodies have been assaulted.

*I really wanted to help my sister, but she wanted to handle it by herself. Supporting her the way she wanted was what I learned to do.–KBG*

*My mom was diagnosed with Stage 4 non-small cell adenocarcinoma (lung cancer). One of my most challenging days was when she decided she wasn’t going to do any more chemo… I had no idea that was coming. As upset as I was, it was her decision to make.–AR*

*Get help for yourself. Take care of yourself. You can't help support others if you are not in a good place.–KW*

Caregiving can impact our health and well-being. Our loved ones are on the front line, and we aren't going to stop helping them — yet we must establish some balance between helping and taking care of ourselves in order to continue to be there for them. Creating balance and caring for yourself are the greatest challenges of being a caregiver and require deliberate effort. Maintaining activities that give you joy and distract you from the serious work of caregiving is a must.

*My husband plays tennis every Saturday morning. After they finish their game at 9:00 a.m., they go to the local McDonald's to eat breakfast, rehash the games (it always astonishes me that they replay every point after the event is over) and enjoy the camaraderie. Keeping this routine was essential for him to maintain balance. The secondary gain was for me. I wanted to hear how everyone was. It helped me stay connected to the "land of the living."–CS*

Ways to take care of yourself can vary depending on what your interests are and what provides balance.

- Being in nature is rejuvenating and grounding. It may allow you to get in touch with your feelings or simply be lifted above them.
- Writing can allow emotions and thoughts to flow. You can journal, write poetry, or write a letter to someone that you don't send (or do!).
- Schedule a time when you can allow yourself to fully feel the emotions that sit right below the surface.
- Yell. Getting into the car and yelling at the top of your lungs is a great release. Yelling is like scribbling: a free form that allows release.
- Cultivate calmness with meditation, yoga, napping, or even wearing a color that helps you feel calm.
- Music evokes, releases, and soothes emotions. Play it, sing, or listen to it.
- Art is a form of expression. Even if you aren't talented, don't throw out this idea. Remember being a child and scribbling? The act of scribbling is a free form and doesn't restrain emotions. Sitting with paint, finger paint, crayons, or other mediums can provide us with a way to release what we feel without the need to be artistic.

### Workbook Chapter 27 Taking Care of the Caregivers *Support*

The chart below can help you decide what you want to do to support yourself.

| **Ideas** | **Yes** | **No** | **Maybe** | **When** |
|---|---|---|---|---|
| Movement: | | | | |
| Walk or run | | | | |

| | | | | |
|---|---|---|---|---|
| Work out | | | | |
| Other: | | | | |
| Other: | | | | |
| Hobby (dance, sports, crafts, etc.) | | | | |
| Be in nature | | | | |
| Writing | | | | |
| Art | | | | |
| Yelling | | | | |
| Meditation | | | | |
| Entertainment (TV, reading, play games, etc.) | | | | |
| Be with children or animals | | | | |
| Other: | | | | |
| Other: | | | | |
| Other: | | | | |

*It’s important to rest so you don’t quit, especially when things are long term. Try to take care of yourself. It isn’t feasible or sustainable to do everything for everyone.–RR*

*I found it helpful not to focus on the disease, but on conversations I always wanted to have with my mom.–MM*

*Message boards and reaching out to others who have similar experiences were helpful.–KW*

*Everyone and every situation are so different. What works for someone may not work for you. Listen and follow your instincts.–SH*

Frankie shows that no matter how much we want to help and are needed, balance is crucial.

### Frankie’s Experience *I Guess We’ll Never Know*

When my dear friend, Carmen, was 36, she was diagnosed with Stage 3 colon cancer. Carmen had to have her entire colon removed. I was in shock that she had cancer and that it was so advanced. Her chance of survival was less than 50%.

I had her move in with me so she could heal, even though I am not good with people getting sick.

I don’t handle cleaning up vomit very well; I feel as if I will pass out. But I stood there holding trashcans for her while she got sick every day. I helped her with her colostomy bag and did things I never thought possible. The only goal was to get her better.

People don’t understand the challenges the caregiver faces in dealing with their own fears, stepping up to the plate, doing things that you once thought unimaginable, keeping faith that everything will be ok and your best friend will be back to normal soon. All of this happens while ignoring your own needs and those of your family, because the crisis demands attention. It was a terrible time and situation, but I would do it all again.

Carmen did heal and has the best attitude of anyone I have ever seen. Her cancer turned out to be a genetic issue. She will continue generating new cancerous polyps but is monitored often and the polyps are removed every six months. She is still my bestie and we talk every day!

I ended up having a heart attack at 48 that they said I should not have survived. Genetics played a huge role, together with many unrelated stressors in my life. The fear of losing my friend and watching her suffer so cruelly made that time the worst years of my life. I wonder how much the stress contributed to my own health situation. I guess we will never know.

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## Accepting Help

*Accept help that is offered, big and small.–NL*

When we are busy helping others, it is essential that we also accept help. The patient is not the only one in crisis: we are, too. Those who know what is going on often want to help. Many don’t know what to offer, so they put out a general statement. “Let me know if there is anything you need.” In our culture, we reflexively say “I’m fine” to such a request. In actuality, assistance would be beneficial for both the giver and the receiver.

It is worth taking time to look at what is on your plate. Many tasks can be parceled out, and you know best who is most suited to do something in specific categories.

### Workbook Chapter 27 Taking Care of the Caregivers *How Others Can Help*

The list below suggests some ways others can help. Check which ones you want, and next to the item, list people you would feel comfortable asking for help.

| Tasks | Possible Helpers |
|---|---|
| Food preparation | |
| Grocery shopping | |
| Have someone organize a meal train* | |
| Household chores (laundry, cleaning, changing beds) | |
| Yardwork | |
| Visiting | |
| Childcare | |
| Overseeing homework time | |
| Carpooling | |
| Taking children out to do something fun | |
| Animal care | |
| Other: | |
| Other: | |
| Other: | |

*Tip: have a cooler by your front door so meals can be left there to reduce exposure to germs and not be overwhelmed by well-meaning visitors.

Sometimes the offer to help goes beyond the mere act, as seen in Ben's experience.

### Ben's Experience *To This Day*

I was going to be 400 miles away from home to be with my wife for a month while she was undergoing a stem cell transplant in Boston. My friends were wonderful, often asking me how things were going during the many months of treatment that preceded the transplant. One friend offered to fly up to Boston to spend some days with me so "I wouldn't be lonely." Initially, I thought that it would be helpful and enjoyable to have his company. After more thought, I realized that due to the type of treatment, resulting in her significantly compromised immune system, I didn't want to be exposed to any unnecessary germs that I could carry into the hospital. I also didn't want my attention divided; we were entering a situation that was unique and extreme.

I didn't take him up on his offer, but it is truly one of the kindest gestures I have ever experienced. What he and my other friends did fed me emotionally and made me feel less alone in the process.

To this day, I feel more connected to those who took the time to offer to help.

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## 28-When the Healing Stops

*My husband, along with his oncologist, made the decision to stop all treatment. This was very upsetting for me. Ultimately, I made peace with it, but it was difficult. During the last three weeks of his life, he was struggling to breathe. He decided he didn't want to struggle any longer, and on that day, he died.–SH*

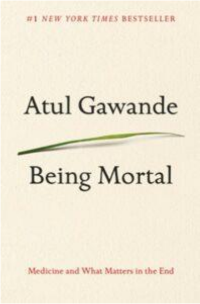
The suddenness and twists and turns of a medical crisis send us through a multitude of reactions. Despite our best intentions to hold onto positive thoughts, our feelings fluctuate. Some days we are full of hope, while other times despair takes center stage. The uncertainty of most illnesses and injuries causes us to be more reactive. Our moods are changed by good test results or unexpected findings.

Some prognoses are grave from the beginning, whereas other situations promise a positive ending. Regardless of the predicted outcome, patients and their loved ones come face-to-face with mortality.

There are times to have frank discussions with medical personnel, the patient, and our loved ones. The notion of this makes many of us squirm. How can we talk to our loved ones about dying? We worry it might take away their hope. Doesn't our doctor know what we should do?

Over the past decade, end-of-life care has rapidly changed. In 1995, a study was published that examined end-of-life care.[1] Titled The Study to Understand Prognosis and Preferences for Outcomes and Risks of Treatment (SUPPORT), one conclusion was that the medical community needed to improve communication with their patients and their families. Specifically, SUPPORT found a lack of communication about prognosis, patient's preferences and goals, and about death and dying in general.

Many physicians don't tend to mention death to their patients, and many patients don't ask; yet patients need better information to be able to plan and have their wishes carried out.



In October 2014, Dr. Atul Gawande's book, Being Mortal: Medicine and What Matters in the End was published, followed by an hour-long PBS special.[2] As a surgeon, Dr. Gawande wanted to develop greater skill in helping patients face end-of-life issues. His writing draws on patients' and families' experiences, as well as his personal experience with his dying father. Dr. Gawande indicates that today's medical community pushes terminally ill patients too far, utilizing last-ditch treatments that can have painful and even harmful side effects while yielding little benefit. Do they assume all patients want to pursue life at all costs? Do they have issues with losing patients or talking about death?

Having a guide for conversations about end of life care can help. The Conversation Project with the Institute for Healthcare Improvement and Boston University's School of Medicine[3] provides free online programs to guide conversations with patients and their families about their preferences for care at the end of life. Additionally, most hospitals and some medical offices have personnel who specialize in working with patients and families around these challenging topics.

> I *was with my brother at his appointment when the doctor told him there was nothing more they had to offer, and nothing was working. He was expecting it, but it was hard to hear. This was in March. He asked his doctor if he could make it through one more baseball season. The doctor just stared at him. He died three months later.–KL*

> *I went to visit my mom, who was dying. She asked me if there was anything that I had to do that day and I said, "No, why? Do you want to get ice cream?" She toddled into her bedroom with her walker and said, "No, we are going to plan my funeral." So that day, we listened to hymns, read Scriptures, and she chose the ones she wanted. We cried and laughed a lot. The service was EXACTLY how SHE wanted, down to the fact it was supposed to start at 11 a.m. sharp, no matter who was late!–AR*

### Resources for Planning Ahead

Stanford Health Care has a good introduction on the legal documents everyone needs to prepare to communicate their end-of-life wishes.[4]

Death with Dignity specifies the requirements of different states.[5]

Special populations require specific planning and preparation; for example, if you have a child who has special needs and/or won't be able to live independently.

Family members with Alzheimer's and other forms of dementia require additional decisions and paperwork.[6]

## Grief

> *"The reality is that you will grieve forever. You will not 'get over' the loss of a loved one; you will learn to live with it. You will heal and you will rebuild yourself around the loss you have suffered. You will be whole again but you will never be the same. Nor should you be the same, nor would you want to."*
> *— Elizabeth Kubler-Ross and David Kessler*

> *After my husband died, preparation for the funeral, the funeral itself, and the long mourning process began. It took two full years before I felt I could begin to move forward.–SH*

We all understand grief in the face of a loved one's death. But some situations lead us to grieve from the beginning of the crisis right through to the end. Grief is related to changes and the trajectory into the unknown. Changes in the patient's functioning, behavior, and personality give us a feeling of loss. We feel like we've lost the person before they die. This is particularly true in cases of dementia and Alzheimer's, in which patients lose bits of themselves along the way. As they lose pieces of their memories and functioning, we lose them again and again.

The death of loved ones adds another layer of loss. We lose parts of our past that they kept for us, and part of our future in the way we envisioned our lives.

No matter when we grieve or what loss we're grieving, most of us share similar reactions. Symptoms of grief include:

- Crying
- Headaches
- Difficulty sleeping
- Questioning the purpose of life
- Questioning your spiritual beliefs
- Feelings of detachment
- Isolation from friends and family
- Anxiety
- Frustration
- Guilt

- Anger

Understanding grief is most often associated with Elisabeth Kubler-Ross, a Swiss psychiatrist. In 1969, her stages of grief, often referred to as DABDA (below), were published. One does not go through these stages in order; humans are much too complex for such predictability. We shift from one to another and back again.

Kubler-Ross's five stages are:

- Denial: feeling numb and not believing what is/has happened
- Anger: experiencing anger about our loss
- Bargaining: wanting to make "deals." "If I get better, I'll go to church every Sunday." "I'll be a better person."
- Depression: feeling empty, hopeless, lost
- Acceptance: good days start to outnumber the bad; we have times of joy, laughter, normalcy. We can think about the one we've lost and revel in the good times.

David Kessler, a colleague of Kubler-Ross's, added a sixth stage: finding meaning. His book, Finding Meaning: The sixth stage of grief, was published in 2019.[7] Kessler has experienced more than his share of loss and trauma. He couples his experiences with his professional knowledge to impart wisdom about an important aspect of adjustment and loss.

When grief does hit, it is all encompassing. It overrides other feelings and occupies our thoughts. During the first year of loss, we mentally and emotionally brace ourselves for the "firsts:" the first birthday, holidays, anniversary of the death, etc. As the year passes and we've somehow gotten through it, our brain adjusts a bit and our guard lowers. The lowering of our guard can throw us into a deeper feeling of loss.

Adding to ongoing challenges in the years beyond the first year is that our friends and family don't always recognize our loss as much as they did during the first year. Many think we should have moved on and adjusted. Loss is painful, and some don't want to see us sad or want to deal with their own sense of loss, so they pull away, causing us to lose support, friendships, and opportunities.

Situations naturally arise that shock us into reliving our loss. Filling out forms that ask for marital status, you face checking a box. Am I married or single, and why does it matter to a new doctor? You meet a parent at your child's school who asks, "How many children do you have?" What do I say? I have four children, or I have three children, or I had four children and one died?

*My Dad and most others don't turn into angels or become blameless when they're dying or upon their death. No one ever knows the intricacies of someone else's relationships.–SM*

*I am profoundly sad and find no joy, at times.–RF*

*Grief, not for death, but for the death of all the hopes, dreams, and preconceived ideas or anticipations we had for our son.–RR*

*I was never a confident person, but after my daughter died, I question whether I have the ability to do things that used to be second nature.–KK*

## What Can Help

How we deal with grief is as individual as how we cope with a crisis. In his book, The Other Side of Sadness: What the new science of bereavement tells us about life after loss,[1] George Bonanno, Ph.D., suggests we seek situations in which we experience laughter and other positive emotions. A break from the pain of the loss is essential. Humans can experience positive and negative emotions at the same time, and when we are grieving, the loss sits in the front row of our hearts and minds.

A 2018 study asked over 600 bereaved adults what types of support were most helpful. Informal social support from friends and family topped the list.[2] The takeaway from this study is to surround yourself with positive people. Those friends and family who can be positive, respectful of your grief, willing to share memories, and "hold the space" are gifts. "Holding the space" refers to active listening and openness to hear what others want to talk about, as well as being with them in silence. Being with someone so completely is one of the most comforting things we can do for another.

Pacing ourselves and allowing time, feelings, and ideas to guide us is an important combination. It is often suggested not to make major changes during the first year of loss (e.g., moving, changing jobs). We can be too impulsive and want to flee from pain. We think that changing our surroundings will lessen the grief, but rushing to do so can cause regret later.

Another aspect of importance is rebalancing the brain. The chronic stress of crisis and loss has impacted our brains. Just like our bodies, our brains need to be rebuilt. This takes time and deliberate intention. One of the best ways to rebuild our brains is to rest! Taking time to sleep, engage in mindless tasks, be in nature or exercise are some of the prime ways to help our brains recover and restore balance.

*In nine months, I had lost my dad, my niece, and my sister. When I came back to Maryland after my sister's services, I took a day and stayed home like a hermit and cried. Then I felt like I needed to get back to life, helping my kids cope with the losses, getting back to work, and returning to life. In retrospect, I didn't give myself enough time to recoup.–AM*

*In my mother's final days, the flurry of activity at my parents' home hit a crescendo with an increasing stream of phone calls, visitors, and deliveries of food, gifts, and drugs. There was a constant buzz at all times, and when our nuclear family arrived from NY and CA, a new swirl of energy — desperate, tense, and fearful — entered the home. The day before she died, it reached a fever pitch. I remember we were all around her in the bedroom, when suddenly, quietly, the energy changed. The noise abated. The air softened as the tension fell away, replaced by a palpable calm. Struggle seemed to cease in that moment, and all that remained was love; pure, beautiful, and distinct. And in that moment, I knew that love was greater than fear, even the fear of death. This has stayed with me.–LO*

## Finding What Works for You

For some, hearing others' experiences is helpful because it makes us aware we are not alone in our feelings and life circumstances. Others find it helpful to write down what they feel and experience. Writing removes any need to censor our thoughts or reactions. We can say whatever we want and not have to deal with anyone's reactions. It gives us freedom to express our grief. Sometimes when we have freedom to reveal what sits inside, feelings and ideas emerge we didn't even know we had.

Engaging in what you determine to be strengthening (e.g., music, nature, laughter, exercise) is important. Doing certain activities without our loved one can be challenging. Finding a new hobby or activity can offer positive paths because they don't have a link to the past. At the same time, keeping a link through a tradition or a new activity to honor your loved one is important.

### Debbie's Experience *Don't Send Me Plants*

Receiving people's condolences upon my husband's sudden passing gave me comfort. To have him and me remembered brought pauses in my grief, but soon I learned, I will never send anyone in such a situation send a plant. Plants need care. They need watering. Some need sunlight. They need attention. Without such vital care, they will die. Don't send me plants. It'll break my heart all over again to see something die.

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### Resources

How To Go On Living When Someone You Love Dies, by Therese A. Rando [3]

Dying Well with Hospice: A compassionate guide to end of life care, by Paula Wrenn & Jo Gustely, R.N.[4]

A compilation about loss from authors who share their experiences in a touching, real and sometimes humorous way. Modern Loss: Candid conversation about grief, beginners welcome.[5]

Websites on grief and bereavement.[6]

Article and video about complicated grief that is well done.[7]

Article about how grief can manifest in our bodies.[8]

The Hospice Foundation site has many articles and videos related to grief.[9]

Elizabeth Kubler-Ross and David Kessler: On Grief and Grieving: Finding the meaning of grief through the five stages of loss[10]

Finding Meaning: The sixth stage of grief, by David Kessler.[11]

David Kessler has a website that offers online grief workshops as well as other resources.[12]

Nora McInerny brings insight into loss and beyond with frankness and humor in her podcast, books, and TED talk. Her podcast, Terrible, Thanks for Asking, has pieces about Nora's miscarriage, father's and husband's death all within a few weeks, as well as conversations with others who have experienced trauma or loss.

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[2] Breen, L. J., Aoun, S. M., O'Connor, M., Johnson, A. R., & Howting, D. (2019). Effect of caregiving at end of life on grief, quality of life and general health: A prospective, longitudinal, comparative study. Palliative Medicine, 34(1), 145-154. doi:10.1177/0269216319880766
[3] Rando, T. A. (1991). How to go on living when someone you love dies. New York: Bantam Books.
[4] Wrenn, P., & Gustely, J. (2017). Dying well with hospice: A compassionate guide to end of life care. Place of publication not identified: Amans Vitae Press.
[5] Soffer, R., Birkner, G., & Arkle, P. (2018). Modern loss: Candid conversation about grief: beginners welcome. New York, NY: Harper Wave, an imprint of HarperCollins.
[6] https://www.mastersincounseling.org/guide/loss-grief-bereavement/
[7] https://blog.sevenponds.com/professional-advice/what-is-complicated-grief
[8] https://www.webmd.com/special-reports/grief-stages/20190711/how-grief-affects-your-body-and-mind
[9] https://hospicefoundation.org/End-of-Life-Support-and-Resources/Grief-Support.aspx
[10] Kubler-Ross, E., & Kessler, D. (2005). On grief and grieving: Finding the meaning of grief through the five stages of loss. New York: Scribner.
[11] Kessler, D. (2019). Finding meaning: The sixth stage of grief. New York: Scribner.
[12] https://grief.com/

## 29-Forever Changed

> *Having lost two brothers, I often consciously think if this is the last time I will see a person. How do I want them to remember our last time together? Then I change my behavior, reactions, and feelings accordingly.–CB*

Every encounter impacts us. The casual passing of a stranger on a street who smiles or frowns affects us, even if we don't think it does. We don't always realize the impact someone else has on us, as the impact sits in our subconscious. Yet, we are acutely aware of how those we love impact us. Through our relationships with them, we are forever changed.

We mourn what we lost, celebrate what we gained, and dream about what our life would be like if they were still here. Even when sorrow bangs loudly from within, the growth we acquired through knowing them remains.

*I think of my wife all the time, and while my overall outlook is positive, it is painful to experience life without her.–KH*

*Carter's illness and death shifted my perspective about love and the importance of family. It reminds me that the fleeting moments I have with my girls are more precious, and that things can change on a dime. The value of relationships that still exist is greater to me now. I care very little about what car I drive or what we are doing on a weekend. Time with family is valued exponentially greater.–RR*

## Unexpected Reactions

No matter the circumstances of someone's medical crisis or death, whether we are patients, loved ones, or caregivers, we aren't truly prepared. Others can try to prepare us about the prognosis, risks of the procedure, chances of recovery, how long they might live, or what caused the accident, but none of that matters when it happens. Our unpreparedness takes front stage and our brains kick into a bizarre spin.

At the moment of the crisis, our minds can be flooded with normal, everyday thoughts that defy the reality of the moment. When my friend came home from work, she entered the house and found her husband lying on the bathroom floor. As she looked at the scene, her mind settled in on the thought that the kitchen floor was an odd place for him to rest. In another flash, she realized he was dead.

### Mea's Experience *No One Is Taking My Car*

At 44 years old, my husband, Joe, died suddenly of a heart attack while playing volleyball with neighborhood friends. Receiving the call, the shock blurred my mind. Days, months, and more passed not quite believing it, particularly as I looked at my 8-year-old son and 4-year-old daughter. Somehow, we trudged through the changes.

Two years after he died, I left work on a drizzly early evening. Popping open my umbrella, I began to walk to the far end of the lot where I had parked. This was my custom because I didn't want any door dings. While walking to my car, I noticed a car parked next to my car's driver's side. The other car's windows were fogged up causing me to think someone was inside the car. I unlocked my front car door, opened it, and pushed the button unlocking the rest of the doors. I pushed my door closed a bit and then opened the back seat door on the driver's side to put in my briefcase. Just as I did that, the front passenger door of the other car opened and a man with a stocking over his head brandishing a handgun got out demanding my car keys.

He grabbed at me and my purse. My mind triggered into fight mode and I batted at him with my umbrella. The gunman likely assessed by 5'2'' frame and umbrella thinking this would be a fight he would win. He got a hold of my purse's shoulder strap and fiercely jerked on it, attempting to get it away from me. He jerked it so hard that my purse was pulled from my hands, spinning me around, and causing me to fall down behind his car. He went through my purse but didn't see my keys. The stocking likely hindering his vision.

At that point, he was joined by the driver both demanding where the keys were. I shrugged indicating I didn't know and started to get up when he hit me with his handgun by my right eye. The driver turned to get back into their car while the gunman dropped my purse and looked for the key in my driver's seat area. Seizing the moment, I got up, ran to the other side of my car. The gunman got into their car and they left with my keys safely in my purse.

Throughout the carjacking my mind sparked with strange thoughts. I knew I was bleeding from the hit with the handgun and I remember thinking, I really like this suit jacket and hope the blood won't ruin it. A moment later, as I was getting up from the ground, it sunk in that hitting him with my umbrella and resisting wasn't the smartest action. As they were driving away, I realized my high heels had come off when I was knocked down. I mentally debated whether I should go back to the other side of the car and get my heels, or immediately run to the office lobby to get help. I ran to the lobby.

In an ambulance on the way to the hospital, a medic gave me a tissue and very nicely said it was ok to cry if I wanted to. I remember thinking, I didn't need to cry. I was grateful. Grateful that I hadn't been shot. Grateful my kids still had a parent.

The police followed the ambulance to the hospital and interviewed me about the incident. The officer took notes and then said, "I hope there is never a next time, but if there is, let them take your car. It's just a possession." I turned to him and said, "No one is going to take away my car without a fight. It was the last thing my husband bought before he died." I drove that car until it couldn't go anymore.

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We all make our own way when a loved one dies. There is no magic, no perfect solution, and no way to avoid feelings about the life that is lost. Lea's son died of leukemia and she shares part of what her loss is like.

### **Lea's Experience** ***We Will Meet Again***

Joey was so talented and determined to do things. He was compassionate. Through all the pain and suffering he went through; he never gave up. He remained strong until his last breath. I was at his bedside holding his hands when he died. It has been 14 years (the exact number of years he lived), and the pain I had that day is still the same. The pain never goes away. I've just learned to live with it. I must believe that he is in a better place and one day we will meet again.

Being a caregiver is challenging. We are forced to try to balance our own experiences while supporting our loved ones. Our feelings fluctuate and surprise us as we move through the ups and downs. Although we can't take away pain, cure someone, or know what the future will bring, our efforts make a difference: we have offered love.

## 30- Moving On

Where we end up on this journey varies. For some, treatment and adaptations continue for a lifetime. For others, surgeries and treatment come to an end. Some people return to their lives without a bump, but most are forever changed.

Understanding the impact of what we've experienced, adjusting to changes, regaining footing, and recognizing unexpected gifts that may have arisen from the experience are all a part of moving on. As we wiggle against the changes that have occurred, many around us say we just need to adjust to the "new normal" of our lives. But, for many of us, post-treatment life is anything but normal. It is acknowledging the *lack* of normalcy that allows us to adjust and regain our footing in order to move on.

### Cindy’s Journey *You’ll Feel Better in the Morning*

As I think back to my adolescent years, I feel lucky. My memories reflect a happy time in my life. Oh, there were times of adolescent angst when I was upset and life seemed out-of-kilter, but I have no recollection of what happened to evoke such reactions. I do remember, though, that I sought my mother’s advice. Her guidance was direct and simple. “Get a good night’s sleep. You'll feel better in the morning.”

Her suggestion led to immediate frustration in my teenager’s brain. Go to bed? It’ll be better in the morning? Humph. Just get a good night’s sleep and wake up? That wasn’t the advice I sought — but as the tears stopped falling, I fell asleep, only to awake the next morning learning my mother was right again. Life did seem better.

Now that my treatment is over, I hope the same will prove true — that I’ll wake up and I'll feel better. However, as the weeks turn into months, my life still doesn’t feel right. My days continue to twist and turn with experiences and adjustments. Once again, I seek advice from those around me. Some say I will find a “new normal.” Others promise my day-to-day life will regain rhythm and shape.

Deep within, I once again hear my mother’s voice. “You'll feel better in the morning.” But this time, it is taking more time for the sun to rise.

## 31-The Other Shoe

### Cindy's Journey *Thud*

Beginning to see the journey from the multiple myeloma treatment begin to fad in the rearview mirror, THUD. The other shoe dropped. An ache in my back nagged at me. Not wanting to be sidelined, I kept up my activities, including tennis and pickleball. Ice packs, cushions, hard chairs, soft chairs, and an occasional lower back brace didn't ease the discomfort. Finally giving in, I stopped my physical activities to see if that helped. Nope. No difference.

The pain became almost unbearable. Tests concluded the cement previously inserted into the space between the fractured vertebrae due to the multiple myeloma "eating my bones" had crumbled. Through compassion, skill, and talent, Dr. Ali Bydon at Johns Hopkins Hospital scheduled me for surgery to insert rods, screws, and a spacer to keep vertebra apart to prevent paralysis. The challenge of the surgery and hospital stay were exacerbated by the pandemic and not being able to have any visitors. I didn't really want to see anyone but Ben, as the pain was too significant to socialize.

Recovery and rehab during the following eight months were progressing as Dr. Bydon expected and then, THUD, another shoe. Pain surged forward only to find the spacer shifted because of a new crack on the vertebrae it sat on. The spacer moving caused one of the titanium rods to break. Back at Hopkins for surgery to replace the rods, insert a different spacer, and remove a left rib required the expertise of three surgeons top in their fields. This time, Ben was able to come to the hospital and stayed overnight in my room to assist me. A better nurse, I couldn't find.

My physical activities are limited, but I can walk and it has been a year since the second surgery.

Just when you think there are no shoes left, another one can drop. I'm embracing my days, believing all will continue to be well, until THUD…

## 32- Now I Know

If I were asked prior to my own health journey, "What are the primary emotions that people experience when going through a medical crisis?" I would have put scared at the top of the list. Indeed, fear rears its ugly head, but I quickly learned that being afraid and other challenging emotions can be strengths that help us move forward to handle what comes our way. We learn worry is important because it leads us to question what needs to be done. Sadness is a gift, increasing our awareness of what we value. Anger propels us to fight for what we need. The support of others reminds us we aren't in this fight alone. Although a medical crisis isn't what we would have chosen for ourselves or our loved ones, through the pain, loss, and uncertainty, we experience bravery, resilience, change, and hope.

### Cindy's Journey *My Old Self*

As I grab onto one of the last warm, sunny fall days to clean out the garage, a neighbor walked by. She expressed how good it is to see me like my "old self" again. We speak for a while, catching up on each other's lives. As she walks back up the hill to her home, her words come back to me: my "old self."

So much of my life looks different now. I can’t work like I used to, my hair is short, my body aches, and fatigue is a constant companion. But then it hits me: I realize that too much of my attention focuses on what has been lost and not on what has stayed the same. A smile settles across my face as I realize that through it all, I am still me. I am still my “old self” — just wiser.