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Simple Things You Can Do  
to Improve Your Quality of Life  
and Achieve Your Best Possible  
Health Outcome

PRACTICAL  
STEPS  
FOR DEALING WITH  
CANCER

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Simple Things You Can Do  
to Improve Your Quality of Life  
and Achieve Your Best Possible  
Health Outcome

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# Introduction

So you've received your diagnosis. You have cancer. Now what? First things first. Take a deep breath, exhale slowly and relax. You're not dead yet. Breathe in again, exhale, and say it out loud. "I am not dead yet." If you can read, breathe, and speak, you are not dead yet. This is a fact. Focus on this fact right now and then set it aside once you are convinced. I am going to help you and I need your attention to do so. When we are done with this book you will have learned to help yourself and you will feel better. That's a promise. Let me say this again: You are not dead, you are not alone, and things are not hopeless.

Trust me on this because I've been diagnosed with eight types of cancer since 1995. More about that below, but for now I want to say that I've walked the path you're walking on and I can help you find your way.

## About This Book

I wrote it for everyone who has cancer, especially for people who have been recently diagnosed or fear they may soon be diagnosed. There are things you can do to help yourself that may not be apparent to you. I want to show you what those things are and give you practical guidance for dealing with them. There are some common problems in the cancer world

that are detrimental to your best interests. These problems are not deliberate sabotage, they are simply artifacts that have yet to be identified and corrected. The main challenge is an absence of specific personal guidance that will keep you positive and hopeful while facing uncertainty. I am going to give you that guidance. I urge you to follow it because it can have a direct impact on your health and happiness. Finally, I want you to reach a threshold where you have learned enough to take control of your personal situation and become your own best advocate. This is possible.

Caregivers and loved ones and doctors will find something useful here, but this is really between you and me. We are the ones with cancer, and right now my primary concern is you. We're in it together and at least some of the things that work for me will work for you.

There are many good books about cancer. There are some great thinkers and writers covering this subject and if you have time to read their books you'll find some beautiful literary and scientific masterpieces. This book is different. It's not philosophical or literary and I am not a scientist. My intention is to create a practical book that can help you quickly and directly by sharing things that I have learned as a long term "professional cancer patient." I want this book to be accessible to everyone with cancer and to be easy to read for the average person. You, the reader, do not need any special skills to improve your life.



## About Me

I was born into a middle-class family in New Jersey in 1959. I went to public school and later to Syracuse University, where I received a BA in liberal arts. I've always worked in technical fields, and I've taken time out in my career to travel and explore other interests. I have lived in the greater Boston area since 1983. I have been very lucky to meet and marry a lovely woman and to ultimately buy a small house and live modestly outside of the city. In many ways I'm just an average person.

In 1995 I was diagnosed with two brain tumors. That marked the beginning of my cancer journey. As I write this in 2024, I have been diagnosed and treated for eight different types of cancer. I have undergone several major surgeries and many minor surgeries. I have undergone radiation therapy three times. I have had chemotherapeutic treatment three times. Some cancers have recurred. Two cancers are rare, uncurable, and fatal, meaning that one of them will eventually kill me unless I die of something else first. There is currently a hint of a ninth cancer emerging. I experience

interactive symptoms and side effects from the diseases and treatments that pile up on each other. It's a wild ride. I stopped working in 2016 so I could manage all of this and take better care of myself. I have some of the best doctors in the world and yet none of them can offer a meaningful prognosis. I am off the charts. At least one scientific paper has referenced my unusual health problems.

I have included a list of my various illnesses and treatments in the back of this book. It isn't necessary to read these things, but you may find them interesting and informative.

I am extremely grateful for all the medical professionals who treated me and kept me up and running, and just as grateful for friends and family who supported me again and again. My wife, Sabine, has been with me through all of this. Without her love and care and attention I'm not sure if I'd still be alive to write this. This is dedicated to her.

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## Part One



# Getting A Grip

Receiving a cancer diagnosis is like being pushed off a cliff. As soon as we hear the word “cancer” everything changes. It sends us into a whirlwind of thoughts and emotions. We feel it first, and then we start to think in words, “This can’t be true. There must be a mistake! Am I going to die? How can this happen? Why me? How could God do this to me?” Panic and fear. This occurs in seconds and it can be devastating. So much so that we may not hear anything the doctor says after delivering the diagnosis. We leave in a fog. Everything has changed and now we must deal with it. And we don’t know how.

Some version of this scenario is true for almost everyone. The details don’t matter. What does matter, what is most important right now, is getting a grip on yourself. You have been pushed off balance at a time when you need all your

emotional and intellectual capabilities to function normally. Fortunately, there is a path for getting your feet firmly back on the ground again. We'll start by building a solid foundation for dealing with what is to come. The first things I want to address are emotions and feelings that create the fog. We all have them and it's completely normal. We also have the ability to manage them and clear that fog. Let's get started by talking about self-pity, an emotional booby-trap that can work against us.

Self-pity is excessive worry and unhappiness with your own troubles. The common phrase is to "feel sorry for yourself." It is corrosive. It creates a sense of hopelessness that casts shade over your entire life. It leads to apathy and loss of drive. Unfortunately, most of us experience self-pity after hearing our diagnosis. It can last for days or weeks or just come and go. This creates two problems. First, it's difficult to make good decisions when you're down in the dumps (and you will be making lots of decisions). Second, if you are dwelling in self-pity, you are missing a golden opportunity. Your overall attitude can have an impact on what is known as patient outcome. Patient outcome means how well you do during and after treatment. People with good attitudes and a positive outlook on life tend to live longer and be healthier and happier than people with negative attitudes. They have better outcomes. This effect is measurable and it is documented. I know, this is hard to believe. I'll explain it in greater detail in the appendix of this handbook. Right now, you need to get busy with managing self-pity. The good news is that there are some very simple and effective

ways to do this, so let's dive right in. Here are four proven things you can do to eliminate self-pity.

### **FIRST: "It Could Be Worse"**

"It could be worse" is a powerful tool. When you are thinking about your situation and feeling down, remind yourself that it could be worse. It can always be worse. For example, you may step out on the street and be hit by a bus and still have to deal with your illness. Worse, right? What if you were living in a poor country in abject poverty and had no access to healthcare at all? There are millions of people who live like that. Worse, right? These examples may sound childish or remote, so add your own example that is relevant to your life. Then make sure that whenever you feel self-pity creeping up, whenever you start to think, "Why me?", remind yourself that things could be worse. This technique is known as "cognitive reframing." It works because it expands the range of what is possible, showing you that you're not at rock bottom. You will find that you can apply this simple technique to other parts of your life too.

### **SECOND: Two Ways to Stop Telling Yourself Negative Stories**

Telling ourselves negative stories is very common. It goes like this: "What if my insurance doesn't cover my health-care expenses? What if I can't work anymore? Who will take care of my kids? I might not be able to handle the

treatment.” These are all legitimate questions and you may have to address them later, somewhere on your path. The point right now is that no one can predict the future. You do not know if these things will happen. Why paint a picture of negativity and worry? You may very well be wrong, and when you look back later you’ll see how much time and energy you wasted. You could devote that time and energy to improving your own wellness. The best way to rid yourself of negative stories is to interrupt them. There are two good ways to interrupt your story.

The first method I’ll describe is called “Pause and Grok.” To “grok” means to take in your environment. It’s like pushing a reset button and it’s very simple. When you catch yourself in a negative story, pause, then use your five senses to experience your environment. Let everything in. What do you see? Is it light or dark? What do you hear? Cars driving by, or a dog barking? Do you smell dinner cooking? How would that taste to you? What does the fabric of your clothes feel like? Smooth or rough or in between? Try this right now. Look away from these words and see, hear, smell, and feel. Seriously, do it right now.

Grokking was taught to me many years ago by a friend who was showing me how to surf a kayak on the open coast of northern California. It’s a high risk environment and I panicked every now and then. My teacher explained to me what it is to grok and I learned to focus 100% of my attention on my situation at any given moment. There is no room for panic or for “internal story telling” when you’re in that moment and observing everything with all

your senses. My teacher had a hand signal for grokking. If he saw me getting in trouble, he used that signal to remind me to pause and grok. Since then I've used this method in many different scenarios and I usually regain my composure. A few minutes ago I asked you to pause and grok. Did you do it? If not you can try right now, or just save it for later. I think you're going to like how it feels.

Here is a second method for interrupting your negative stories and any other negative train of thought. I call it "Do I want to feel this way?" Here is an example of how it works in everyday life. Let's say you're driving a car on the highway and somebody abruptly cuts you off and forces you to step on the brakes. For many people, this unleashes a flood of emotions that we have come to call "road rage." This response comes directly from a part of your brain (known as the amygdala) that is responsible for your survival. It happens automatically, and it bypasses another part of your brain (known as the prefrontal cortex) that oversees rational thinking. In an instant, we go from rational to irrational. This is completely normal. It doesn't mean that there is something wrong with you, but you don't want to stay in this state of irrationality for very long. To rapidly recover from it, ask yourself, "Do I want to feel this way?" How you answer the question doesn't matter. Go ahead and feel anger, or realize that you would prefer to feel happy, or excited about something positive. The point is that asking the question engages the prefrontal cortex, bringing rationality back into the game. This is also normal. The cool thing is that you have the capability

to fine tune the process. This is how some people survive when things get difficult. You can be one of those people (maybe you already are one of those people). Now let's go back to interrupting negative stories in our specific circumstances.

When you are telling yourself a negative story you are feeling anxiety and other uncomfortable emotions that can interfere with your thinking or make you feel bad. As you recognize these emotions, ask yourself, "Do I want to feel this way?" You don't, so use that break in your story to shift your attention elsewhere. Something better will pop up without you even trying. The challenge with this technique is that you have to recognize the rising feelings of anxiety and the story you're telling yourself. If this is a problem for you, practice by asking yourself the question several times a day so you get used to it. You will discover that you can use it in many situations. Every time you are angry or frustrated or worried, just ask yourself the question, acknowledge that you would rather feel differently or not, and you will free yourself up. This kind of self-monitoring can change your life in so many ways, and the people who know you will notice it.

Interruption techniques work because they block your story and your flow of emotions. You cannot continue your story when your attention is directed to something else. While you are using these techniques, you are taking control of yourself and using some human potential that you may not know you had. This feels good (and feeling good is what we all want). You might find yourself making a habit out of using these tools. I recommend it.

### THIRD: Find Gratitude and Joy Every Day

I really love this and I do it every day. Gratitude is humbling and beautiful. So, what do you care about? Your dog? Your children? Sex? Adventures? Reliving past experiences? Music, art, fixing things, helping other people, riding a bicycle, reading a book, talking with a friend, helping a stranger? Whatever it is for you, remember it and let it flow. Let it be something that makes you smile. The joy will occupy your mind. You cannot hold joy and self-pity simultaneously. And amazingly, this joy will flow right into the gaps that you created with your interruption techniques. Isn't it cool how all of these things work together?

Here's a little story to illustrate the power of joy. Many years ago when I was learning kayak surfing on the west coast, I caught a perfect wave and got a very long ride on a very beautiful day. Suddenly a brown head poked out of the water right next to me. It was a sea lion, so close that I could touch it! It was looking at me, watching me! That sea lion surfed along with me like that for what seemed like minutes (probably 20 seconds, but who knows, time is hard to gauge when you are deeply in the moment). Finally the wave started to break up. The sea lion ducked into the water and disappeared. To this day, I smile and feel good every time I recall that wonderful day. How lucky can one guy be?



## Summary:

You can beat self-pity and overcome strong emotions. It isn't always easy at first. I have had to beat it again and again, as if I were slipping backwards. There is no switch I can flip to eliminate self-pity forever, but I have found and learned techniques that work for me. Here they are:

1. It could be worse (change your point of view)
2. Pause and grok (interrupt a negative story)
3. Do I want to feel this way? (interrupt a sudden change in your emotional state)
4. Find gratitude (experience joy and crowd out self-pity)

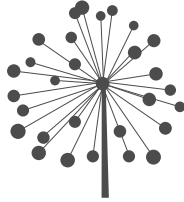
You are not alone, but using these techniques is up to you. Practice these four things. If it's difficult for you, start with just one. I recommend "It could be worse" because it's easy to remember and it's very effective. If you can use any of these techniques and make progress with them you are moving in the right direction. You are policing your thoughts and emotions. You are getting a grip on yourself. You are now better positioned to make decisions and you have prepared yourself to be more effective for some of the important discussions that lay ahead of you. I cannot stress how important it is for you to get on this path and follow it. Improvise when necessary, but don't stop or give up. If you are doubtful about the underlying science and psychology, you can think of these techniques as "tricks" or "brain

hacks” or God given mercies that you are only discovering now. The important thing is that they work. They have all worked for me and I’m pretty sure they’ll work for you too.

Are you still with me? I hope so, because I want to congratulate you. You have improved your attitude, beat back self-pity, and aligned yourself with seeking the best possible outcome. This is really an accomplishment!



## *Part Two*



# The People In Your Life

While you were busy getting a solid grip on yourself you were also interacting with some of the most important people in your life. Spouse, parents, children, siblings, friends; it could be anyone or any combination. You have also been interacting with doctors and other people in cancer world, as well as people who are not that important to you. This is a good time to sort out the roles that people play in your life. Who are those people? What do they do for you? Are they capable of playing new roles that you envision while you deal with illness? What will you need for support? If your illness is simple and easily treated (as many are these days), the chances are that you won't need a lot of support. If this applies to you, you can skip this section and move on

(or go back to Part 1 to review and practice the techniques that helped you empower yourself). But you still might find it useful to at least think about the people in your life and how everyone fits in. You did the heavy lifting in Part One. This part is a little easier. Let's get started.

- Who are you closest to in your life? Who has supported you during other difficult times in your life? Write down their names. Somewhere on that list there is the person who is your “rock,” the person you can rely on. The person who is always there for you.
- Inventory your own responsibilities. Are you taking care of anyone (children, spouse, elderly parents, etc.)? Do you cook for others, do the food shopping, the laundry, the cleaning, the miscellaneous other work around your home? Do you pay the bills? If you drive, do you transport other people to school or work? Make a list of all of your responsibilities.
- Now it's time to bring your rock into this process. Hold your list of people next to your list of responsibilities. How does it look? Can those people handle any of your responsibilities if necessary? If so, match the names to the tasks. If there are still gaps, can any of your people manage the process of finding other people or other ways to fill the gap? Who would that be? This is the time

to handoff to your rock. Let them handle this. Do it together if you want to, or just take a break for yourself and do something else, like remembering something joyful in your life.

- It's OK to offload some tasks completely, especially the ones that you are not responsible for backfilling. For example, if you volunteer for a club, let them know that you need a break for a while and let them backfill. It's also OK to carry on with some or all of your responsibilities if you want to. This depends entirely on you and your health status. Choose the path that is best for you. Aim for the best possible outcome for yourself.
- It's helpful to have other people to talk to besides your rock. Some friends may shy away from this for reasons of their own. Others may surprise you.
- There is no stigma in talking with a therapist. They are expert listeners. They ask good questions.

Communicating with those who care about you is important, but frankly, it can be draining. When I was first diagnosed with a brain tumor, the word got out and a lot of my friends started calling. I'd explain to them what was happening, what the proposed treatment was, how I was feeling, etc. Then they would start asking a lot of questions (out of the goodness of their hearts), which I would patiently answer. Sometimes a friend would get upset, or cry, and I found myself in the odd position of

consoling them while I was the guy with the brain tumor. A thirty-minute call like this can grind you down. Now imagine having two or three of those calls every day. It was stressing me out, which is not good when you're dealing with an illness. My solution was to start a private blog and make it accessible to all of my friends. I sent a bunch of e-mails telling everyone that they could get the latest news and updates by visiting my blog. I told everyone how much I appreciated their support, and when we talk or correspond in the future, we wouldn't have to re-hash the health and medical issues. Instead, we could talk about the fun or interesting stuff, just as we always had. It worked! I still maintain that blog to this day.

Now I want to remind you that this is all about you and protecting yourself and moving yourself toward your best possible outcome. As in Part One, you are exerting control over outside influences. How you handle this is up to you. The important thing is that you're handling it. If you step on a few toes along the way, don't worry about it. You can take care of that at some future time. Your friends will understand. Here are some ways that you can set up a communications channel:

- Use a free blog system, such as Google Blogger, to set up a simple blog.
- Some hospitals have pre-existing communication systems that are similar to a blog but are already set up. Ask your doctors if this is available.

- You don't have to write a lot of words, but it's good to post often. Remember that your "audience" cares about you and wants to stay up to date on your status.
- Some people find that writing is therapeutic, but if you don't like to write, ask a friend to write for you. It's a nice way to spend time together.
- If you don't like blogging, you can create a Facebook group or an Instagram account or a YouTube channel or whatever suits you in this era of social media. You can do all of this with a smart phone, or you can ask your rock to organize this for you.

This approach worked for me, but it may not work for you. You may enjoy the daily phone calls, or you might want to reach out to people proactively. By all means, do what feels right to you. And you can always change course if your first choice isn't working out the way you want it to.

Before we leave the subject of people, I want to warn you that some people in this world can drag you down. It may be negativity or rudeness or general thoughtlessness. It may be someone who annoys you or gets under your skin for whatever reason. It may be a colleague that you never liked in the first place. If you know someone like this, that person is probably not that important to you and you do not have to tolerate them. It's in your best interest to block them out. Send them to your communications channel.



Don't take their calls. Ask your rock for help with this or enlist other friends who may also know that person. You have more important things to do. Take care of yourself first.

Several years ago when I was a "guest" in a hospital for three weeks, there was a nurse assigned to me who really annoyed me. Who knows, maybe it was my problem. I was in pretty bad shape at the time, but I just didn't want to be around that nurse. I never complained, but the wise and wonderful nursing supervisor approached me one day and asked if there was anyone on the staff that I didn't get along with. If so, she could change the schedule so I would never see that person again and it would remain confidential. The change was made and my daily quality of life improved. I am happy to say that this happened only once on my journey, and in every other case I've received excellent nursing care. I am extremely grateful for this. Just thinking about those nurses, male and female, who cared for me through some very difficult times, brings a tear to my eye. And that is the power of gratitude.

## Summary:

So far we have covered two of the most important things that will move you toward your best possible patient outcome. In Part One we went through some simple but effective techniques for keeping yourself grounded and balanced. Here in Part Two we've identified your "team" and how you can shift some of your responsibilities to other people. This kind of planning is both practical and useful for reducing

anxiety. If any anxiety remains, you know how to interrupt a negative story. These things fit together. In the short period of time that you've been reading this handbook, you may already feel an improvement in your confidence and your sense of well-being. Congratulations (for the second time) for doing the work and coming this far! Do the work, take the reward.



## *Part Three*



# The Importance of Words

## Understanding the Connections Between Words, Attitudes, and Best Outcomes

You know by intuition how powerful words can be. “I love you” has brought immeasurable joy to so many people. It can sweep you off your feet and flood you with positive emotions. Just three words. Can just one word rock your world? I think so, in the right circumstances. The word is “Yes.” Imagine hearing “Yes” after you propose marriage. One word can change the course of your life. I want you to reflect on this for a minute and pair it with Part One, where we talked about joy and how experiencing joy can

improve your attitude and move you toward the best possible outcome. Oddly enough, just hearing the word “joy” can trigger a memory of something wonderful that in turn produces joy. This is so amazing. Try it right now. Think “joy” and just let it happen. It will flow without your conscious effort. There are other words in your personal vocabulary that will produce the same affect. The name of a person or a place. Words from a song. Something someone told you that you cherish. A prayer.

It took me a while to figure this out. Here is how it works. Words affect attitudes, and attitudes affect patient outcomes. Therefore, words affect patient outcomes. The connection between words and attitudes has been sitting right in front of our noses forever, though we may have never noticed it. But what’s really important is the connection between words and patient outcomes. This is irrelevant for lots of people, but it’s super important for you and me right now, because we are on the path to the best possible outcome for ourselves. Words matter.

I was recently treated for a recurrence of prostate cancer. When this recurrence was verified, it sent me into research mode and I started reading lots of scientific papers. I immediately came across the phrase “biological failure.” This indicates that the first treatment was not fully effective. The word “failure” bothered me. Then I learned that treatments after biological failure are considered “salvage” therapy. Salvage makes me think of a rusty ship being pulled up from the bottom of the sea to be sold as scrap. The words “failure” and “salvage” have negative connotations. I found

this to be depressing. I stopped the emerging stream of negative emotions (Do I want to feel this way?) and moved on, eventually finding information that was helpful and inspiring. I stayed on the path. By the way, the diagnosis of the recurrence showed that the cancer remained localized in the prostate. It could have spread throughout my body, so it could have been worse.

Back in the “About This Book” section, I mentioned that cancer world still contains artifacts (words, in this case) that can knock us off the path to a best possible outcome. Don’t let this happen to you. Whether you are talking with doctors or friends, or reading about your illness, expect to hear things and find things that could make you unhappy. Be ready for it. You have the techniques to shut down anything negative and maintain a positive attitude. Every time you do this it’s a huge win! You will maintain the full use of your intelligence and keep negative emotions in check. This is good, because you still have decisions to make and other things to attend to in life.

## Fighting Cancer is a Flawed Concept

For some reason there is a common belief that “fighting” cancer is the way to go. I see this a lot. “She’s a fighter,” or “He lost his long battle.” The belief that fighting is the answer can cause a couple of problems. First, imagine that you are sick and not feeling well at all. Then someone tells you that you need to fight harder. That person is unwittingly putting the burden of your illness on you, as if you were

responsible for it in the first place and it will be your fault if you keep getting sicker. None of that is true. It is not true. But it can make you feel awful. It is subtle because it's easy to perceive this as encouragement, and it was meant as encouragement by whoever said it. If someone is telling you to fight, here is how you nip it in the bud. Use what you know to neutralize that awful feeling (Do I want to feel this way?). Then tell that person that you appreciate their support, but please stop talking about fighting because it exhausts you and is not helping you. When you explain it to them, you are actually helping them to become better supporters. If this person persists and is not in your inner circle, block them. Call on your rock for help. You can re-visit the personal relationship later, but right now it's more important to stay on your path.

Here is the second problem with “fighting” cancer. A fight has only two possible outcomes, win or lose. If you are continuously fighting, you will eventually drop your guard or get tired. If one thing goes wrong, if you have one setback, you can feel like you are losing or that you have lost. No one likes losing. It can take a toll on your attitude, and it is your objective to maintain a great attitude. If fighting is getting you down, drop it. Climb out of the trench.

You can replace fighting with a better concept that gives you more freedom to influence your journey. Your cancer is a part of you and you may as well accept that. Fighting it is like fighting yourself. Instead, you can dodge it, embrace it, dance with it, swim with it, swear at it, laugh at it, and yes, you can fight it from time to time. Change your approach

whenever you want to. Go with whatever feels best at any given time. In practice, have some ice cream. Get someone to read you a story. Get a massage. Go somewhere. Scratch a dog behind the ears. What is it that you would like to do? Does anything stop you from doing it? If so, what's the next best thing?

Experiencing things that make you feel better can have a major impact on your attitude and therefore your best possible outcome. If you decide that you need to fight, to get tough so that you can make your way through something difficult or painful, then go ahead and fight. Fight for yourself, not against yourself. Give it everything you have. When you do this, when you enter "fight mind," notice that you are suppressing negative thoughts and feelings to concentrate on one specific thing. This makes you a better fighter. Soldiers sometimes do this when they are in danger. Their thoughts of friends and family and worries about money can be deadly distractions. They put those thoughts in a separate "compartment." Psychologists call this compartmentalization. It can be very effective.

## Summary:

While we are talking about words, did you put together the connections between words, people, and getting a grip? It's all interrelated. Seeking joy (Part 1) can be better than fighting. Your rock can help you block people who use language that disturbs you (Part 2). Just one word can make you happy (Part 3). Of these three parts, I want to emphasize



how important Part One is. The techniques you learned there are simple and effective. They are foundational for your journey through cancer world. If you have a minute, go back and review them.

## Part Four



# The Prognosis

A prognosis is a prediction or forecast of your likely outcome. It is an educated guess. At some point you will ask your doctor for a prognosis, or that doctor will just give you one. It could be something positive, like, “Everything is great, we caught this early and you’ll be fine.” Or it could be something less positive, like “I’m afraid that this is incurable and you don’t have a lot of time left.” That second one is hard to take. It may be even harder than the diagnosis where you first learned that you had cancer. Most of us will fall somewhere in between the extremes, but the prognosis can create a lot of anxiety. Use what you learned from “Getting a Grip” to avoid going over the cliff for a second time.

Now I want to address the elephant in the room. You are going to die eventually. It may be from cancer or more likely, something completely different. You may be dead in

a week, or you might live for another 10 or 20 or 30 years. Predicting the precise time when you will die is difficult until you are very close to death. As you get older you are getting closer to death from many different causes, but you still can't know exactly when that will happen. This is true for all people, not just people with cancer. Your prognosis can make you feel like you're doomed (this is yet another example of the power of words), but none of us are "doomed" any more than any other person. I recommend that you not focus on death. You know it's inevitable so why bother? If there are practical things you need to do, such as creating a will, just do it and move on. Then focus on your future, even if only one day at a time. No negative stories. I have been told more than once that ignoring death is denial. I see it differently. To me it is a deliberate bias toward health and well-being. I feel much better when I think and feel that way. Sure, something will kill me eventually, but I've got plenty of things to do in the meantime. That's where I focus my attention. Do I think about death sometimes? Of course I do. I just don't let it take over. I put it in a mental box (compartmentalization) and set it aside.

OK, we have recognized the elephant, now let's go back to prognosis. The good news is that the prognosis is sometimes wrong. It is not the final word. When I was diagnosed with peritoneal mesothelioma in 2014 I was stunned by the severity of the disease and the very short survival times associated with it. The survival statistics suggested that I would be dead in less than a year. When I was discussing treatment possibilities with my doctor I short circuited the

prognosis discussion by telling him that I didn't want a prognosis. The doctor said that was good because he could only make a wild guess. Then I asked him if it was possible for me to live 20 years and die of something else. He nodded and said yes, it's possible. That was good enough for me. That's what I anchored on.

Survival statistics will play some role in your prognosis. If you have studied them or are planning to do so, here are some things for you to consider.

- Statistics do not apply to an individual. They apply only to the “universe” of people who were part of a specific study. They cannot predict your specific outcome.
- When you were treated matters. Survival statistics are backward looking out of necessity. In order to capture 10-year survival rates, it is necessary to include people who were diagnosed or treated 10 years ago. But for so many illnesses, treatments have improved over the last 10 years. This doesn't show up in the long term data. In my case, my treatment for peritoneal mesothelioma was very different from what people were receiving ten years prior.
- Where you are treated matters, but the statistics usually don't show that. If you were treated at a medical center by specialists, all things being equal, your outcome is likely to be better than

someone who did not have access to the best and latest treatments. This is not considered in most studies. In my case, I was fortunate to have access to the best available treatment.

- Some patients show up at a doctor's office with very advanced cancer. They usually do not live as long as a patient who has the same cancer but was diagnosed early. This is not visible in the statistics.
- Some patients are in poor health while others are in excellent health. The benefit goes to the people who are generally healthier. This does not show up in the statistics.
- Every statistical analysis has a certain amount of uncertainty, partly for the reasons I've mentioned above. When analysts try to control for variables, uncertainty increases.

There are a lot of people who know a lot more about statistics than I do. Some may disagree with one or more items in my short list. That's fine. If this situation comes up, ask that person to correct my error and explain things in greater detail from their point of view. My intention here isn't to give you an education on statistics (something I'm not qualified to do). I just want you to know that there are nuances and you are not locked into what you have read and what you may have been told.

## Summary:

Prognosis can be a rocky road. Reckoning with death is uncomfortable for many of us. But we have a good rationale for reframing our thoughts about death and setting them aside. We also know how to breakdown a prognosis. Finally, we have methods to deal with our own emotions and responses that we learned in Part 1. Remember to use them and stay grounded. If you slip up now and then it's OK, but I recommend that you always go back to Part 1, remind yourself about what you can do, and then do it. Winston Churchill once said, "If you're going through hell, keep going." I think it's good advice.



# Conclusion

That's it, you made it through all four parts. I have shared with you the most important things I've distilled during my years of juggling cancer. They are the things that tap into your inner strength and allow you to move forward and achieve your best possible outcome. You now have a foundation and framework for organizing yourself in preparation for what may be a challenging journey. I've kept this short to drive home the point that this is not complicated. It might be a lot to digest all at once, but it's easy to go back and look at it again. If you haven't shared this with the people who are close to you, now is a good time to do so. They'll get as much from it as you have and you can talk about it together and share insights.

As I said to you in the beginning of this book, this is personal. It's about me and you. I hope I have brought you to a place that is better than the place you were in when we started. I know it sounds corny because I don't know you personally, but I'll be thinking about you and all of the other people like us. We have more strength and resilience than we might have thought. We have a lot inside of us and a lot to give. So open up the floodgates and have at it! I wish you the very best!





# Appendix A

## Details of the author's cancer

Who am I, and what are my credentials? I am anyone, and I don't have any credentials. I am not a doctor, a scientist, or a celebrity. What I have is an uncommon background. I'm a guy with a lot of cancer. As I write this I am managing eight different kinds of cancer, two of which could kill me in short order. If I worried about this everyday I'd be a wreck, but I do ruminate from time to time. In fact, I've been ruminating on my cancer experiences since 1995, and that's where this book is coming from. Now let me show you my "resume." Here is how I identify my eight different types of cancer:

1. Peritoneal mesothelioma - Cancer cells that form a plaque on the wall of the abdomen and eventually encase organs and form tumors. It's not curable and is considered to be rapidly fatal. I was treated for this in 2014.
2. Pleural mesothelioma – Similar to the peritoneal version except it forms in the chest cavity and can eventually encase the lung and invade the chest wall. It's not curable and is also considered to be rapidly fatal. I was treated for this in 2018.

3. Melanoma – A form of skin cancer that can be fatal if it metastasizes. It's treatable by removing the lesion if it has not spread. I've been treated for this twice.
4. Basal cell carcinoma – A form of skin cancer that is rarely fatal. It is easily treated by removing the lesion. I have lost track of how many times I've had these lesions removed, but it is more than 30. This is an ongoing process.
5. Renal cell carcinoma – A malignant cancer of the kidney. If caught early it can be removed from the kidney or the entire kidney can be removed. I was treated for this surgically in 2010 on the right kidney, and again in 2014 on the left kidney.
6. Prostate cancer – A form of cancer that can be cured or neutralized, although it can return later. It is fatal if it metastasizes and spreads to other parts of the body. I was treated for this in 2010 and again in 2022.
7. Atypical meningioma – A cancer of the brain that grows on the lining of the brain and pushes inward, causing symptoms. Atypical meningioma is known as Grade 2. It is neither benign nor malignant, but it can become malignant. It grows faster and is more likely to recur than Grade 1 meningioma. I was treated for this in 1995, and a second tumor was treated in 1996. The first tumor recurred in 2008 and I was treated again.

8. Lung cancer – During surgery for pleural mesothelioma, an unknown lesion was removed from the right lung. It was determined to be Stage 1. If caught early, the cure rate for this can be over 80%. I was treated for this in 2018.

Treatment for this kaleidoscope of cancers has included four craniotomies, adjuvant radiation to the brain, hormonal treatment and radiation to the prostate gland and a second round of radiation twelve years later, laparoscopic surgery to remove a kidney tumor, cryo-ablation to destroy a second kidney tumor, massive cytoreduction surgery and omentectomy with HIPEC for the peritoneal mesothelioma, radical pleurectomy, decortication, and HIPEC for the pleural mesothelioma, simple excision for melanoma in-situ, and multiple excisions for basal cell carcinomas, including multiple separate MOHS surgeries and skin grafts for BCC on my face and eyelid. This all started in 1995 and it continues right up to the present moment. So there you have it. I'm a professional cancer patient.

In spite of these problems, I still ride a bicycle (only e-bikes now because I lost lung capacity as a result of chest surgery), shovel snow, wash the car, paint the garage, etc. I just do it more slowly now and with greater difficulty. I'm 64 years old as I write this, so the normal aches and pains are catching up with me too. How have I been able to hang on and stay active for all of these years? Beyond luck, I don't really know, but I suspect it has something to do with attitude and living an active physical life. After my

first brain surgery in 1995, I measured my recovery by my cycling performance. The day I got home I rode a trainer in my apartment for 60 seconds and then went to bed, exhausted, for the rest of the day. After two months I could ride 20 miles. At the end of that first 20 mile ride I thought, "I'm back." It was a joyful moment. During recovery I never assume that I've been limited or damaged in some way. That would be telling myself a negative story. I simply carry on. If there are limits and damage I'll find them, and indeed, I have found quite a few. I still carry on as best as I can.

# Appendix B

## References

Earlier in this handbook I told you that the methods I learned and shared with you were not made up out of thin air. There is research and science to back this up. If you want to delve into this, the references here can be looked up by web searching the title and publishing information. Some may be behind a firewall requiring payment. Some may be free but require signup. Some are open and available to everyone.

Novotny P, Colligan RC, Szydlo DW, et al. A pessimistic explanatory style is prognostic for poor lung cancer survival. *J Thorac Oncol.* 2010;5(3):326-332. doi:10.1097/JTO.0b013e3181ce70e8

*Note: This paper shows that lung cancer patients with optimistic attitudes tend to have better outcomes than those with pessimistic attitudes.*

Gould SJ. The median isn't the message. *Virtual Mentor.* 2013;15(1):77-81. doi:10.1001/virtualmentor.2013.15.1.mnar1-1301

*Note: For me personally, this essay gave me hope when I was diagnosed with peritoneal mesothelioma. Gould had*

*the same disease, diagnosed in 1982. He went on to live 20 years and then died of something else. This essay helped me understand prognosis and statistics.*

Impact of Ductal Carcinoma In Situ Terminology on Patient Treatment Preferences JAMA Intern Med. 2013;173(19):1830-1831. doi:10.1001/jamainternmed.2013.8405

*Note: This shows that the words and terminology used by a doctor when discussing a DCIS diagnosis can have a direct impact on the treatment chosen by women with this diagnosis. Using the word “cancer” in the diagnosis causes some women to choose more invasive therapies. Hearing “abnormal cells” causes some women to choose less invasive therapies.*

The word ‘cancer’: reframing the context to reduce anxiety arousal; Centre for Behavioural Research in Cancer Control, Curtin University, GPO Box U1987, Perth, Western Australia 6845 PMID: 14705284 DOI

*Note: This paper shows that patients react poorly to the word “cancer” when it is used in a diagnosis. Changing the use of the word reduces stress caused by the negative attributes associated with the word “cancer.”*

Improving mental health by training the suppression of unwanted thoughts; Science Advances, 20 Sep 2023 Vol 9, Issue 38

*Note: This long and technical paper shows that suppressing negative thoughts leads to better mental health. This*

*confirms the idea that interrupting negative stories and reframing using “It could be worse” and other techniques can be effective.*

Experiences of Self-Criticism and Self-Compassion in People Diagnosed With Cancer: A Multimethod Qualitative Study; *Front. Psychol.*, 13 October 2021 Sec. Health Psychology Volume 12 – 2021

*Note: Another long and technical paper showing that self-pity has a negative impact on cancer patients, whereas self-compassion has a positive impact. It defines the elements of “self-criticism” and in those elements you will find what we commonly call self-pity.*

You don't have to read these papers, but they're here if you feel like you need to substantiate the techniques shown in the handbook. You will find dozens, perhaps hundreds of other papers relevant to these subjects. Reading them may require you to parse the paper to extract what is relevant to you specifically. If you choose to do this, I recommend starting with sections with names like “abstract,” “results,” and “conclusions.” These summaries are easy to read. Learning to read the whole thing is a specialized skill. You may have to study statistical analysis, look up unfamiliar words, and learn to comprehend complicated graphics. These are good skills to have if you decide to read technical papers that cover an illness that you or a loved one might have. Please remember that in Part Four, Prognosis, we looked at gaps and nuances that are not always obvious, especially in the



subjects of mortality and survival. To better understand this, I recommend that you read the second entry above, called “The median isn’t the message,” written by Stephen J. Gould.