

Welcome to Team Positive

We know illness is a tough time, and each person affected by the illness will react in entirely different ways given a variety of factors. This includes their circumstance, mindset, spiritual beliefs, and personality traits as well as socioeconomic status and access to quality care.

This book has been designed to help you gain a broader and deeper perspective of what has been found to work so that you can more easily build a support network of your own. My father and I explore and share with you the concepts and actions that helped us, our family, and those we worked with afterward move through such a challenge. This book includes evidence-based tools and techniques that are clear and easy to use and that I have found to be highly useful, both personally and professionally, as a clinician.

The primary objective of Team Positive is to help you—hero and caregiver—find new ways to work together as you navigate a life-changing diagnosis.

While there are some excellent resources out there, few address the process that a support group will go through or provide a list of useful strategies. There is also far too much information online that should best be labeled as “not useful”—in other words, these resources fall under the headings of “gloom and doom” and “horror stories.” Some of these resources can, in fact, be detrimental. Agreeing to a positive mindset and reliance on the team support system will help to buffer against these effects.

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I liken this Team Positive process to that of a flock of geese flying off in a designated direction. When the point person becomes overwhelmed and tired, they then fall back into the V formation so that they can get inside the pocket, get away from the full brunt of the effort, and regain their strength while another takes the lead for a while. For my family and for many since then, this type of framework made it possible to move through such challenging times.

In some cases, the worst-case scenario did come to pass with the loved one dying. However, it has been others' and my experience that when the concepts found within this book were practiced, the whole process was more validating and supportive, and the actions taken by all were meaningful. You can have this outcome too.

I invite you to continue. You are already in action. Get acquainted with the fundamental aspects of this approach. Dive into the basic nuts and bolts to see how this model would look and work for you. Pay attention to the sensations and emotions that drew you to this book in the first place, to how you feel as you turn the pages, and how you might anticipate this approach could alleviate some of the current suffering you are experiencing.

Recognize that one of the emotions you are feeling is hope. Hope is one of the greatest gifts that I, my family, and the medical and therapeutic community wish to offer you. If you have any questions at all as you read this book, please don't hesitate to send me an email and I'll get back to you as soon as I possibly can. I offer this because I know

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from my own experience how important it is to have a stable and robust network behind you.

My father was fortunate in that we were able to pull all these concepts together and that his medical community at MUSC Hollings Cancer Center in Charleston, South Carolina, was absolutely phenomenal. They were there every time we had a question. My wife also did well with this framework despite the slower process of diagnosis. Again, like my father, once she was at Brigham and Women's Hospital, she too found a clinical program and support that was beyond belief. In both situations, the medical staff's approach was open-minded and progressive, and they worked hard to respond quickly and compassionately, making the family feel like they were heard and understood.

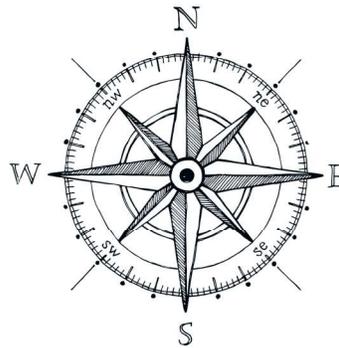
You can have these outcomes, too, by assembling a fantastic network of folks in all the right places. The Team Positive approach works to ensure that you will be pulling from the best of all resources available. It is a model that my family and those I have worked with have benefited from multiple times to varying degrees.

Please know that my heart goes out to you heroes (let's not call them patients) and your support network. Know that there are going to be times when you will be tried to your limits and pushed beyond your boundaries. But with some guidance (and a little luck), I think you will be able to take the actions needed to engage and feel stronger, confident that there is a process to help you through this medical journey, one small step at a time.

It's all about being Team Positive.

Part I

The Situation





1 The Initial Impact

It was just another day, doing the usual actions, thinking the same general thoughts until some novel experience, something unexpected, came crashing into your life compelling you to act. Everyone's story always begins with something out of the norm that suddenly, without warning, changed their lives and those around them forever.

One woman reported how she went to see her doctor a week before her vacation with flu symptoms only to discover she had a growth just outside her stomach. It had been pressing against the wall of her stomach lining, causing many of the symptoms that she had been experiencing for weeks.

Another was of a man who, on his usual bike ride, noticed a lump on the inside of his leg. He thought it was just

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a muscle pull, but after a few weeks with no improvement, he checked in with his clinician to find out that it was a sarcoma (a malignant cancer).

Another man was visiting his dentist for a toothache that had been making his throat sore. However, during the visit, it was discovered that he had a form of throat cancer in which the inflammation had been causing the tooth pain.

In my wife's case, since her symptoms began as she was fast approaching forty, she chalked up her seemingly unrelated complaints to age. Sensitive stomach? That's just what happens when you hit your forties. Joint pain? Must be the beginning of arthritis, since, again, approaching midlife. Fuzzy eyesight? That must be normal for someone later in life. After months of seeing different doctors for each different complaint, her eye doctor connected the dots and set her on the path that led to a definitive diagnosis of Crohn's disease (an inflammation in the intestine)—the answer to her symptoms that she received on the day before her fortieth birthday.

For many, there were no signs or symptoms that anything was seriously wrong. Disease was discovered during a routine check or more dramatically when they ended up in an emergency room, only then to discover that they were dealing with a much more serious diagnosis like cancer, Crohn's, diabetes, heart disease, or some other ailment. I also think it is important to note that many mental illnesses would fall into this category as well.

In a way, these examples were of those who were lucky in that they were able to catch the illness before it could gain a strong foothold and end their story. For the fortunate, this

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new occurrence, while it did not finish their story, gave them a challenge or a quest that they did not want to undertake but had no choice. The experience became an unwanted chapter in their lives, yet ultimately one that had a profound impact on their lives and the lives of those who came to their aid. What do you do? What do we do?

Everyone's approach to a scary diagnosis will be different, and yet, in many ways, many of the plans will look similar from afar. This book has been designed to address many of the similarities, yet they are not one size fits all. Each hero, each champion, and each support team will have to adapt the information within to meet their situation. Everyone has different resources, beliefs, rules, and tools to draw upon, and this book will give guidance to all involved.

I encourage you to use this approach as needed and consult specific sections for each type of person involved, from the hero to the support members. Some sections address the individual perspectives, while others are tools to help with the given situation. Feel free to change and adjust the concepts and drop sections you do not like. Make the tools more personal and be creative in filling in the gaps, including changing the name from Team Positive to whatever you want to call the group. You have been doing this your whole life. This challenge is no different.

In making this program your program, you will increase the likelihood that your application will be tailored to meet your specific needs and, therefore, be far more effective.

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The Undeniable Quest

A quest is a journey made in search of something or a long and difficult effort to find or do something.

From mythology to modern day, often the story begins with a happy man, woman, girl, boy, and sometimes animal living a normal life, one with some challenges, but nothing outside their ability.

Then, something big happens.

Frodo finds a ring, Luke gets pulled into an intergalactic battle, and Odysseus gets blown off course. None of them wanted to get drawn into the quest, yet all of them engaged with the situation as best they could. You have most likely already faced similar challenges. Welcome to your latest quest.

Think: Has there ever been anything truly meaningful in your life that was not difficult to undertake?

Loss of Control

One of the most prevalent fears people have is that of losing control. When you heard the words (“You have cancer.” “Your x-ray shows a blockage.”) that outlined your diagnosis, this fear most likely became real. Something terrible has happened. It does not matter if you prepared ahead of time, took care of yourself, or did

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nothing special at all. It does not matter if you're the one with the diagnosis or the support person.

The immediate impact causes actual physical sensations and a realization that you have lost control. In reality, though, when it comes to external aspects of the world and the forces of nature, you never really had control to begin with.

We are quite good at keeping a focus on what is right in front of us and rarely, if ever, honestly take into account that our reliance on certainty is limited in a world that is always tentative and uncertain. It is precisely this unrealistic belief that creates anxiety in our lives. We all think that we are reasonably accurate in being able to predict and manage the future. This belief is a bias.

Yet, the key to getting through your most recent challenge will be in giving up the parts of your life you cannot control and having the courage to address the ones you can, as embodied in the Serenity Prayer.

Grant me the serenity to accept the things I cannot change, courage to change the things I can, and wisdom to know the difference.

Living one day at a time, enjoying one moment at a time, accepting hardships as the pathway to peace, taking the world as it is, not as I would have it.

Trusting that in the end, my life will have had meaning and that the actions that I took when it was most difficult were ones that mattered.

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Be ready and willing to face the inherent and unavoidable uncertainty of the future. While this may seem overwhelming, you can do this. And you don't need to do it alone. You are here reading these words that contain ways to

- Strengthen and/or build your support network,
- Increase your psychological flexibility through new coping strategies,
- Build a larger capacity to accept and move through the pain, sorrow, and fear of your private experiences, and
- See how others who went before you were able to truly focus on what mattered to them so that no matter the outcome, the life lived during this time of challenge was done with dignity, grace, and meaning.

What You Can Do Right Now

This applies to both the person with the diagnosis as well as the support team.

Team Positive Rules to Use Right Now

1. Do not go looking for information on the internet.
2. Do NOT go looking for information/solutions on the internet.
3. If you look (which you will), look for credible websites from reputable institutions like the Cleveland Clinic, the Mayo Clinic, disease-focused organizations such as the American Cancer Society or Alzheimer's Association, or university patient education resources.
4. Stay away from internet chat groups filled with horror stories.
5. Accept that you/your team will make mistakes and forgive.
6. Think in terms of probabilities and assume the positive outcomes.
7. Get a notebook. Keep it with you. Write all questions in here. Take this notebook with you to every doctor appointment.
8. When you fall into a pattern of worrying, ask yourself, "What matters right now?"
9. Remember you are doing the best you can with the tools that you have.
10. Keep to your routine as much as possible.

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Consider the following ways to think:

Push yourself to act on the evidence, the facts at hand, without adding more to the situation than what can be accounted for.

Don't be fooled by believing the misinformation out there on the internet, in magazines, and in the news. Your best bet would be to avoid looking anything up—that is, stay off the internet. However, given our need to feel as if we are taking action and our mind's need for a solution, you will probably look anyhow.

On top of this, you will hear about sources from friends, family, and friends of friends. Most of what you will find is not useful, is out of context, and, most likely, does not apply to your situation.

It is okay to take a look but try not to get bogged down in looking for a way out. Continually looking for the magic pill or a miracle process can distract you from what really matters.

It is normal to look for a way to try to escape, avoid, or control unwanted personal experiences, but these strategies are short term and will not work well in the long run.

Feel free to take a look if a source seems promising, but keep a critical eye as you read, watch, or listen to the source. Once you have read the information, let it sit, bring it up at the next clinical visit, or ask someone else on your team to look into it.

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If you do look, give yourself a time limit since the chances are, while the resource might provide some promising information, it will also link to other information, which will be disheartening.

Begin to think and live in terms of probabilities no matter how small.

Probability is simply the likelihood that something will happen. It is not a guarantee, just a comparison to other instances and the outcomes of those situations. It is easy for your mind to focus on the negative margin, especially when it is larger than the desired outcome.

In other words, if the survival rate for a particular diagnosis is only 10 percent over the next ten years, your mind will naturally focus on the negative number, the 90 percent chance of not making it through versus the 10 percent chance of making it through.

While this comparison is only natural, since the mind's number-one job is to solve problems, this will only lead to anxiety over something that is outside your control. Instead, remember to focus on the positive outcome as if it will be your outcome. That 10 percent chance is better than no chance, and by keeping your focus on that window of opportunity, you will be more likely to achieve small goals for living thirty, sixty, and ninety days at a time. This strategy will become useful in between tests and scans, especially when treatment is complete.

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Avoid guarantees and the expectations that accompany such promises.

Be wary of any product or approach that states it will work all of the time. If there was a diet, a pill, or a secret treatment that worked this well, it would be used widely and often and would be well known.

Believing in outcomes (especially when we desperately want the result) sets up an expectation bias. When these expectations are met, the approach appears to work (that is, our expectation is confirmed), but when these biases are not confirmed, we are more prone to emotional instability.

Accept yourself as an imperfect being who will make mistakes about the future.

We have a wide variety of emotions, yet what we do with these emotions is either useful or not useful. We tend to emphasize the ones that are not useful since this is one method of learning (from mistakes and making corrections).

The problem is that we often make the outcomes a personal flaw and begin to craft a story about ourselves. For example, “I should have taken better care of my body” “Should have taken more time for myself” or “I should have stopped smoking earlier in life.” At this point, these thoughts are not useful and will have a negative effect on your outcomes. They will pull from your energy reserves and reinforce negative experiences.

Remember, in all situations you are doing the best you can.

Think of a time in the past when you wish you had done something differently. If you had known the best course of action back then, would you have deliberately ignored it? Of course not. You made the best decision you could have, given the circumstances you were in, plus you relied on the knowledge and skills you had at that time.

In short, we do the best we can with what we've got. Rest easy in this knowledge.

Notice when you fall into the habit of worrying. When that happens, ask yourself, "What can I do now that will matter?"

A lot of people spend a great deal of time reviewing their past behaviors and thinking of how they could have done better. Again, if you knew then what you know now, wouldn't you have done it right?

What else could you be doing with the time that you are currently spending on what-ifs, could-haves, and should-haves? What matters in your current situation that you will devote this time and energy to? This is key to developing a meaningful life—one that matters to you.

Initial Actions

While future chapters will give you skills and techniques you can use to help address issues as they come up, what

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do you do right now? You just received the news about an illness and are struggling with what this all means. Your emotions are moving from confused to overwhelmed, states of despair to deep gratitude, anxiety due to the uncertainty of possible outcomes and everything else in between.

One of the best ways to prepare yourself for the long journey ahead is to develop a skill that you already possess but rarely use. This is the ability to become more aware of what your mind is doing, being able to notice when you have shifted tracks, and being fully in the present moment, right here, right now. Increasing your mindfulness skills is vital to being able to move through this challenge with grace and emotional stability.

Here are two simple exercises that can help begin to develop this skill. These are not only useful for the hero, but also for anyone who is part of Team Positive. Every one of us could be more mindful of when our focus on the present moment wavers. Learning this skill is important because it allows you to focus on what truly matters so that your challenge is overcome in a way that is the most meaningful to you.

Simple Morning Mindfulness Ritual

One of the first tools I introduce in working with those dealing with a chronic, life-altering challenge (as well as just about any anxiety-induced problem) is this simple mindfulness ritual. The goal is to begin to strengthen the ability to remain in the present moment. This includes

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being able to notice when the mind shifts from the task at hand (focusing on an object) to something else.

The exercise is deceptively simple. Focus on what you eat or drink for breakfast. One of the most straightforward ways to do this is with a cup of hot coffee or tea. Simply hold the beverage gently in your hands and work to keep your focus on it.

Notice the feel of the container in your hands, the heat from the drink, the smoothness or roughness of the cup, the curvature of the glass. Pay attention to your left hand, then bring your awareness to the right. Move through each of the fingers noting any sensation you feel. Notice the steam rolling off the top of the cup and the coffee grinds or tea leaves swirling around on the surface of the cup. Bring your attention to the smell of the beverage and then take a sip, focusing your attention on the taste and where in your mouth and on your tongue that the flavor registers.

Your mind will wander. This is to be expected so don't get hung up on the fact that this has occurred. When your mind wanders, simply notice the thought and then bring your attention back to the subject at hand. Do this for at least five minutes.

In doing this exercise, you are developing a new skill that will be essential in helping you distance yourself from overwhelming thoughts and emotions, freeing yourself to be able to choose an action that matters.