

Session 1: Introduction to the Guidebook

Key Points in this Session



Photo: Mike Keller

Tibetan prayer flags in base camp on the north side of the world's tallest peak, Mt. Everest. Every climber starts by being overwhelmed by the magnitude of the challenge ahead. Our first challenge on the cancer climb is to overcome the magnitude of our diagnosis and begin moving forward in small but important steps.

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Session 1: Introduction to the Guidebook

Introduction

CD 1, Track 1, 15 seconds/MP3 15 seconds

Welcome to the first session in the 12-part guidebook *Cancer Survivorship from the Inside Out – A Step-by-Step Guide for the Newly Diagnosed*. This guidebook and its accompanying audio guide are part of the larger online *Climb Back from Cancer Survivorship Program*. The purpose of the program is to make your life easier, your treatment better and your future brighter. In short, I want to help you make the best of the rest of your life.

A Rough Start

CD 1, Track 1, 41 seconds/MP3 41 seconds

When I was diagnosed with the very aggressive blood cancer, acute leukemia, things did not look good. Ninety percent of the cells in my bone marrow and 40 percent of the cells in my bloodstream were cancerous. Without treatment, I had less than a year to live – and that was probably a generous estimate. Needless to say, I was scared.

Our 1st Challenge

CD 1, Track 1, 1 min. 2 seconds/MP3 1 min. 2 seconds

Getting past the initial shock of our diagnosis is often the first challenge we face. If you've just been diagnosed, your head may be spinning. Your heart could be racing. You might be angry. You could feel lost. You may feel alone. You're probably frightened. I mean, who wouldn't be? I certainly was when I was diagnosed.

It's okay to feel afraid. In fact, it's perfectly normal and completely understandable to feel whatever you're feeling right now – from numbness to rage, and fear to anger – or just about anything across the spectrum of human emotions. It's equally acceptable to express those emotions. In fact, it's healthy to get them out – to a point. If you're angry and you want to punch something, don't punch a hole in the drywall. Punch a pillow. And don't throw a chair through a window or go on a drinking binge either. You'll have to fix the window and tomorrow you'll wake up with a hangover and still have been diagnosed with cancer. So that's not going to ease your burden, it's just going to add to it. Besides, you've got more important things to do right now than repair windows and recycle empties. For starters, it's time to start taking charge of your situation.

1st Things 1st

CD 1, Track 1, 2 mins. 13 seconds/MP3 2 mins. 13 seconds

When we're diagnosed the first thing we need to know is that no matter what we've been told, no matter what our diagnosis, there is still hope. It could be hope for complete remission, a cure and a complete recovery. Or, it might be hope for a peaceful end to this life before we move on to the next dimension.

Is that sad? Of course it is. Is it frightening? Absolutely. But although there's a possibility of that happening, chances are it's not going to.

The Good News

CD 1, T1, 02:40/MP3 02:41

Why? Because the good news is that across all cancers today – all cancers – two out of every three people diagnosed survive the disease. That's right. *Across all cancers today – all cancers – two out of every three people diagnosed survive the disease.* That means that the number of cancer survivors is, in fact, exploding. There are now more than 15 million of us in North America and our numbers increase by about a million every year. *A million!* That means that chances are, you're going to survive this. Chances are, you're going to make it. And if and when you do, you're going to have an opportunity to make your life better and your future brighter.

Across all cancers today – all cancers – two out of every three people diagnosed survive the disease.

An Inner Everest

CD 1, T1, 03:25/MP3 03:26

I have a great deal of empathy with anyone diagnosed with cancer. Before I was diagnosed, I spent years as a mountain climber. I was fortunate enough to be a member of three self-guided expeditions to the world's tallest peak, Mt. Everest – living proof that I'm a slow learner! I finally reached the peak on my third expedition. When I returned home safely, I thought Everest would be the biggest challenge I'd face in my life. But three years later I came face to face with an even bigger mountain.

My Diagnosis

CD 1, T1, 03:59/MP3 03:59

It was Aug. 10, 2000. My then fiancée, Cecilia, and I were meeting with a blood specialist in an examining room at the local hospital. Dr. Man-Chiu Poon was a short, slim man who knew intuitively how best to communicate with his patients and he read my Type A personality *perfectly*. He correctly concluded that he needed to get my attention. My life depended on it. So he came straight to the point: "I confirm a diagnosis of acute myeloid leukemia," he said. "Without treatment, you have less than a year to live."

The words seemed to hang in the air like sinister vapors, twisting weightlessly. They hardly registered in my brain. They simply hung, like a noose. For a few seconds I couldn't breathe. Then I choked out the first words I was able to get out of my mouth: "What if I do nothing?"

Dr. Poon leaned forward and looked me straight in the eye. He didn't intend to be harsh or insensitive. His goal was to be absolutely honest and I will

always be grateful to him for that. He said, “You’re screwed.”

The words hit me with the force of a Mack truck. Instantly, my life shattered into shards. First, I was dazed, almost numb, completely disoriented. I couldn’t speak. I couldn’t focus. I couldn’t even think. I couldn’t accept that I had cancer. Why me? I’d exercised daily, eaten right and lived what I thought was a clean life my whole life. I hadn’t smoked or done drugs of any kind. Heck, I hadn’t even drunk anything stronger than herbal tea, skim milk and apple juice. How could I possibly have cancer? More to the point, how could I possibly have cancer *now*? At 42, I was in the prime of my life. But without treatment, acute leukemia is 100 percent fatal.

Our 1st Lesson about Cancer

CD 1, T1, 05:55/MP3 05:55

That’s when I learned my first lesson about cancer. Cancer is completely indiscriminate. It can touch the life of anyone, anywhere, at any time. So the question isn’t just “Why me?” It’s also “Why *not* me?” No one’s immune. Everyone’s at risk. And there’s no sense blaming ourselves for what we have or haven’t done in our lives that might possibly have caused it. Guilt doesn’t bring us anywhere except down. Even if you’ve been a smoker, there’s no way of knowing what *really* caused cancer to enter your life. No one knows.

**Cancer is completely indiscriminate.
It can touch the life of anyone, anywhere, at any time.**

Leading cancer researcher, psychologist and co-author of *Mindfulness-Based Cancer Recovery*, Dr. Linda Carlson, advises that a little introspection as a result of our diagnosis is natural. It’s also necessary if we’re to move forward. But she says we can’t allow ourselves to become preoccupied with our past. We have to do everything we can to let go of the past and forge ahead in the present. In my view, the time of our diagnosis is not the time to be beating ourselves down. It’s the time to be building ourselves up. So the sooner we can get past the “why” questions and get on to the “*what do we do now?*” question, the better. Even as we honor our emotions, it’s important that we also focus on what to do next.

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get on to the “what do we do now?” question, the better.**

An Important Perspective

CD 1, T1, 07:19/MP3 07:20

Gratefully, most cancer diagnoses aren’t nearly as time-sensitive and urgent as mine was. In most cases (and chances are you fall into this category), instant action isn’t necessary. In fact, it’s probably ill-advised. A wise, thoughtful

and informed decision made expediently but carefully is better than a snap decision made fearfully. Hopefully, we'll have help making that decision. In my case, that help started with Dr. Poon. As a hematologist, he specialized in treating blood disorders and diseases. But in some ways, he was also a coach. "Here's how it's going to work," he explained. "I put my 50 percent in, and you put your 50 percent in, and together we have a chance. But if I put my 50 percent in, and you don't put your 50 percent in, we only have half a chance, and we can't have half a chance with cancer."

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The Healing Partnership

CD 1, T2, 00:00/MP3 08:21

This guidebook is about our figurative half – our 50 percent. It's the part of the partnership between our medical care providers and us that many survivors, including me initially, can overlook. It's our answer to cancer. And while our medical care professionals are doing their work from the outside in, we can be doing our own from the *inside* out. That won't guarantee that we'll survive. But it will help ensure that we maximize our chances.

While our medical care professionals are doing their work from the outside in, we can be doing our own from the *inside* out.

The Why

CD 1, T2, 00:28/MP3 08:51

I've developed this guide because nothing like it existed when I was diagnosed. When I was diagnosed, I looked around for someone who could tell me the most important steps I needed to take and in what order. Everything seemed like a top priority. My life was at stake and everything was coming at me way too fast. I was having a hard time even understanding what was happening to me and dealing with my emotions, let alone deciding what to do next. If you can relate to that, we begin to understand each other.

My Treatment

CD 1, T2, 00:58/MP3 09:21

Because my cancer was so widespread throughout my body, my chances of surviving acute leukemia at that time were less than 15 percent. My treatment was three separate week-long rounds of non-stop continuous infusion chemotherapy 24/7 as an inpatient. That's a total of over 500 hours, including 120 hours of high-dose chemotherapy designed to virtually eliminate my immune system at the time. As you may know, our immune systems include all those wonderful blood-borne cells that work together to stave off infection, viruses and parasites. After my chemotherapy, I experienced one of the most radical, invasive and risky medical procedures known – something called an

adult blood stem cell transplant. That's the modern-day equivalent of a bone marrow transplant. First, they eliminate your old and defective immune system with chemotherapy. Then, at the eleventh hour, they rescue you with the building blocks of a new immune system. For more than three months while this new immune system is taking hold – *IF* it takes hold – your life hangs in the balance. Something as common as the common cold can quickly develop into something life-threatening. So to say that I'm happy to be here would be an understatement. I'm thrilled and immeasurably blessed.

Transplant Day

CD 1, T2, 02:21/MP3 10:43

On the day of my transplant I was so weak from treatment that I couldn't stand for more than a minute. In fact, I timed it. It was 53 seconds. I couldn't stand for more than 53 seconds. I was naked, vulnerable and at the will of a Power far higher than Mt. Everest. My body was laid bare, as was my soul. It was more than humbling. It was overwhelming – just like it had been when I'd looked up at Everest for the first time. It was immense. This time, though, I wasn't just breathless. I was clinging to the last strand of a rope called hope.

The Survivor

CD 1, T2, 03:02/MP3 11:24

I don't know how you're feeling right now. What I can say is that I feel deeply for you. And I feel *with* you. I know what it's like to feel the fear, go through the biopsies, and experience the uncertainty, lost sleep, blood tests and endless anxiety. I've lived in the limbo land between tests and results and spent hours and hours in waiting rooms and treatment rooms and weeks in hospital. I know what it's like to feel like you've lost control of your life and wonder if you'll ever, ever get it back. That's how I felt. And however you're feeling, I honor and respect that too.

My 2nd Cancer Experience

CD 1, T2, 03:44/MP3 12:06

Ten years after my cancer experience, a routine colonoscopy showed that I had a preliminary form of bowel cancer. All of a sudden, all the memories of my first cancer experience came flooding back to me. Visions of weeks of chemotherapy and months in hospital swirled in my head like demons. A wall of worry hit me like an avalanche. It put a lump in my throat and a knot in my stomach. But fortunately, my worst fears never materialized. I had surgery and made a rapid recovery. That's why I want to help. The things I wish I'd known then, I know now. Most importantly, I know how. And I'd like to share some of that knowledge with you.

Today

CD 1, T2, 04:29/MP3 12:51

Today, I've been leukemia-free for more than 15 years. I have the great good fortune of being one of less than a few dozen people ever to regain an elite

level of fitness after an adult blood stem cell transplant for acute leukemia. In short, I've made a 100 percent recovery. It's beyond my wildest dreams. Hopefully, my voice is the voice of your future. It's the voice of a survivor. I'd like it to be a voice of hope for you.

Coaching

CD 1, T2, 04:59/MP3 13:21

I'm not going to pretend for a minute that I have all the answers, or that this guide is the last word on cancer survivorship. Of course it's not. Sharing knowledge and experience like this isn't counseling or psychotherapy. It's designed to maximize your potential. What I'm going to share with you in this guide doesn't in any way replace or supersede the opinions or recommendations of a doctor, psychologist or any other medical professional. It's strictly my opinion. Nevertheless, what you're about to read has been exhaustively reviewed by a broad team of doctors, nurses, psychologists, nutritionists, patients, survivors and caregivers, amongst others. Over a period of more than two years, I spent thousands of hours researching and preparing this material. I've combined that knowledge with my two cancer experiences and the experiences of the many other cancer survivors with whom I've worked for the past decade as a *Climb Back from Cancer Coach*. The result is what I've learned and what we've all learned together. And we're still learning. So, like everything in life, this program is a work in progress.

Two Climbing Tools

CD 1, T2, 06:11/MP3 14:33

This guidebook and the audio guide that comes with it are for anyone touched by cancer, with any type of cancer. This guidebook is designed to help you get to some of the most important information as quickly as possible. With those two climbing tools – this guidebook and its accompanying audio guide, I'd like to be your climbing guide on this medical mountain; a type of climbing coach, if you will.

Benefits

CD 1, T2, 06:33/MP3 14:55

In this program we're going to work together to maximize your chances of surviving cancer and thriving beyond it. Our objectives are to optimize your nutrition, hydration, thoughts, rest and physical activity. I'm also going to help you manage your emotions, reduce your stress and maximize your mental, physical, emotional and spiritual resilience. I want you to be able to stay focused on what really matters. And what really matters is to be able to move from fear to effective action. We do that by channeling our time and our energy not into fighting, but into healing.

The 7 Steps

CD 1, T2, 07:12/MP3 15:34

We're going to cover seven steps. I'm not going to even pretend for a minute

that something as complex as a cancer experience can possibly be broken down into seven neat little steps. It can't be. But it's important to start off on the right foot. Because once the first steps are behind us, we can climb higher up the mountain.

The 7 Steps are...

CD 1, T2, 07:35/MP3 15:57

Step 1: Get the Right Information

Step 2: Develop a Treatment Plan and a Personal Health Plan

Step 3: Choose Your Team

Step 4: Prepare Yourself Mentally

Step 5: Measure Success by Effort and Honor

Step 6: Execute with an Adventure Attitude

Step 7: Keep Climbing!

Overview of the 7 Steps

CD 1, T2, 08:07/MP3 16:29

The 7 Steps are designed to provide you with a method of coping with the chaos, anxiety, uncertainty and change that come with a diagnosis. Think of them as hand holds on a climbing rope. And we're all tied in to that rope. Our rope isn't just anchored in my experience as a *Climb Back from Cancer Coach*. It's also anchored in the experience of many other survivors. The 7 Steps are arranged in priority. First, we'll start by talking about how to get the right information about your diagnosis and prognosis. Then we'll move on to your treatment options and personal health plan. After that, we'll talk about how to choose your support team and what you can do mentally to prepare yourself for the climb ahead. Finally, we'll talk about how to set yourself up for success, implement your plan and adapt to whatever the future brings.

CAN/WILL

CD 1, T2, 09:00/MP3 17:22

During my treatment, one of the ways I stayed active was to take walks around the ward with my bag of chemotherapy up on my I.V. pole. With every step I took on the ward I repeated a mantra I'd used while preparing to climb Mt. Everest. It was just two words: "CAN" and "WILL." With every step I'd say to myself "*I CAN get better, I WILL get better.*" I said it over and over and over again – not a dozen times, not a hundred times, but thousands of times. Because when our subconscious minds hear something often enough, sooner or later we begin to believe it.

The Summit

CD 1, T2, 09:41/MP3 18:03

I believe that if you follow the 7 Steps in this program, you CAN and WILL take greater control of your health. And when we take greater control of our health, we take greater control of our lives, especially our quality of life. Our goal in this guidebook is to maintain the highest quality of life possible for as

long as possible. That’s the summit we’re aiming for.

Your goal is to maintain the highest quality of life for as long as possible.

We Are All Survivors

CD 1, T3, 00:00/MP3 18:25

On this climb, you are not alone. Whether we’ve been diagnosed with cancer for five minutes, five weeks, five months, or 50 years, if we’re alive, that makes us all survivors. To be who we wish to become in the future, we must first start in the present with the force of belief. So today, and every day from this day forward, although your medical team may call you a “patient,” you’re not just a patient. You are a survivor. We all are.

You’re not just a patient. You are a survivor.

Our Medical Mountain

CD 1, T3, 00:33/MP3 19:01

You see, there *is* a way up this mountain. And it’s climbed the same way all mountains are climbed – one small step at a time, around the crevasses, past the avalanche slopes and through the rock bands, upwards towards the peak. Sometimes we take a step forward only to take two steps back. But climb we must, because to do otherwise is to give in to our own frailties and fear. To climb, we can’t focus on falling. We have to focus on climbing. We have to focus on our feet and the small steps we can take today to take us from where we are now to where we want to go. And the key to unlocking that door is having the courage to take the first step. Because once we’ve taken the first step, we’re off balance. So we take another and another and another. We break through the paralysis of fear and we come to a really important realization – On the other side of fear is freedom.

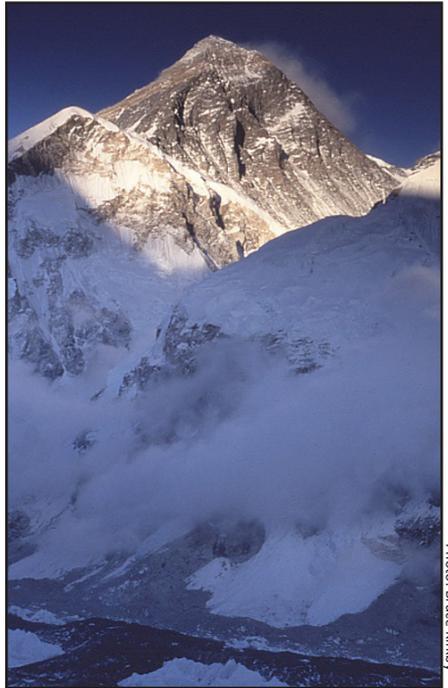


Photo: Bruce Kirby

“On the other side of fear is freedom.”

– Alan Hobson

So lace up your boots and throw on your backpack. Grab your parka and cinch up your helmet. We're all tied in to one climbing rope and we're going to climb this mountain together. We CAN maximize our quality of life for the rest of our lives. We WILL maximize our quality of life for the rest of our lives. This is your *Climb Back from Cancer Coach*, Alan Hobson, saying I'll see you in the next session. Until then, let's...*Keep Climbing!*

