



BALD
IS
BETTER
with
EARRINGS

A SURVIVOR'S GUIDE *to* GETTING
THROUGH **BREAST CANCER**

Andrea Hutton

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WITH EARRINGS



*A Survivor's Guide to Getting
Through Breast Cancer*

ANDREA
HUTTON



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DEDICATION

This book is dedicated to my family and friends.

Especially:

Richard, my wonderful husband, for loving and supporting me in sickness and in health, and without whom there would be no book.

Jeremy and Marisa, my incredible children, who are the most amazing young adults and who make me proud every single day.

Alan and Carol, my loving parents, who have always been there to care for and support me.

Old friends in Seattle who came to chemo, cooked, and walked with me.

New friends in California who, thankfully, do not have to do any of those things but still choose to walk with me.

To those who are now unfortunate enough to need this book—I hope you find something here to help you, comfort you, and give you hope.

Dedication

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INTRODUCTION

Labor Day weekend 2009. The beginning of the rest of my life. The weekend I crossed the street from normal to Cancer Girl . . . and then, thankfully, to survivor. The next year would be filled with the pain, scars, fears, needle pricks, tests, results, hair losses and gains, weight losses and gains, sleep deprivation, fatigue, drug reactions and interactions, and the million and one other experiences that would challenge, exhaust, and exhilarate me and everyone in my family and circle of friends.

I wish this were a singular experience, but it is one shared by millions of women around the world. Whether it's an epidemic or not, breast cancer is a part of every woman's life. If you don't have it, you fear it. From the mammograms designed to detect it, to the walks and ribbons raising money to stop it, we are inundated by *breast cancer awareness*.

I don't care how aware you might be—a diagnosis throws you into a tailspin so fast you lose your bearings, breath, and possibly a breast or two.

With two teenage kids, a few moves around the country, and various job experiences, I figured I was pretty well equipped to handle just about anything life could throw at me. Boy, was I ever wrong. There's nothing like being diagnosed with a life-threatening illness to remind you that you are just a collection of cells and moving parts that can turn against you at any time. I thought losing those pesky twenty pounds and raising two kids were tough. What was I thinking? With breast cancer, losing that weight was easy—nothing like a little chemo diet to get you started.

When I was diagnosed, I wanted to know everything. I educated myself as much as possible. I read every book, article, and Web site I could find and talked to everyone I knew, but nothing would prepare me for the experiences of surgery, chemotherapy, and radiation. Part of the problem was that I wanted to know what everything would *feel* like. What tricks could I use to ease my pain and discomfort? Was I the only one who felt certain things? What did they mean by “fatigue?” Where *exactly* would my hair fall out, and how? I wanted a guide—a how-to for the Cancer Girl I had become.

For me, at least, there just wasn't enough of the right kind of information out there. I didn't care what the normal breast looked like and how the cell walls of tumors were constructed. I really wasn't interested in all the biology—I wanted to know what to expect after surgery when I looked at my mastectomy scar. I wanted to know how to begin to come to terms with this diagnosis, and what the treatments would really mean for me and my family. I wanted to know how bad the nausea would really be, what it would feel and look like to be bald, and what I could possibly do to help myself feel better during this awful time in my life. So I asked a million questions, kept notes, and wrote a blog along the way so I could, perhaps, write it down for others—maybe offer some small help to the new woman who would hear those horrific words: “It's cancer.”

This is not a medical text. You will not find descriptions of breast tissue or the chemical components of chemotherapy drugs. You will not find every single question answered or every experience covered. Your journey is your own, and nobody will have the exact same one. I cannot tell

you how you got here or where you're going next. However, this book is, quite simply, the book I tried to find when I was diagnosed. A plain and straightforward (and hopefully sometimes funny and uplifting) how-to for a few of the situations you may find yourself in now that you've heard those scary words: "You've got breast cancer." This is just one of many resources that may keep you from getting run over by a bus as you cross the street to my side.

HOW TO READ THIS BOOK

Now that you've been diagnosed, you'll want to know what to expect. I'll tell you about the tests, the chemo, shaving your head, being bald, the radiation, the emotional and physical roller coaster you've stepped onto, in roughly the order that things happened to me—the diagnosis, the tests, surgery, chemo, radiation, and everything that comes after. You can go to the Contents page and read just the parts that relate to what's happening to you in real time. The tricks for surviving chemo. How to keep your skin from crisping during radiation. How to keep track of your meds, and so on. Or you can read the whole book from start to finish. I wrote this book to be your BCCB—breast cancer companion book. I hope it provides some answers, solace, and even a chuckle or two.

My Story

THE LUMPS

On Thursday, August 20 I felt a lump in my right breast. I'd found a bunch of weird things over the years that resolved after I got my period or were gone the next day. This one felt different. I called my doctor, who examined me and assured me it was just a cyst. I was forty-one years old with no risk factors for breast cancer, so we didn't think much of it. It felt round and solid, the size of a soybean. I kept touching it. The only thing that made me nervous was that it was a little painful. I searched the Internet for clues, and it certainly seemed most likely to be a cyst. I had a regular mammogram scheduled in a few weeks, but my doctor decided to set up a diagnostic mammogram sooner, on Friday, August 28.

I learned my most important lesson that day: Never go to a mammogram alone. You need a boson buddy. I tell everyone to *always* have someone go with them, because *this* is where you find out you might have cancer. It's in the way the nurse will let you know the doctor would like more pictures. It's in the way she changes from bubbly and cheerful to quietly efficient as you go back for more images.

After an excruciating mammogram, I went back to the waiting room while they checked the results. Then the technician came to tell me the doctor needed more pictures—that is, more uncomfortable squashing. Then back to the waiting room. The technician reappeared and whispered in my ear that the radiologist wanted to do an ultrasound.

This is where your heart drops to the floor. I went back to the examining room and lay down. The nurse and the radiologist started the ultrasound, and I could tell immediately I had cancer by the way they were pointing at the screen and being oh-so careful not to show anything on their faces. I was lying on the table thinking, Oh my God, I have cancer. I can't believe this. And I'm not saying anything because they're not saying anything. Until finally I can't take it anymore, and I said, "Obviously it's not good, so when are you going to tell me?" The radiologist says, "Let's not get ahead of ourselves. We need to look at a few more things." Sure, right. Did you guys not see the elephant that just walked into the room? A big, scary elephant with the word "cancer" written all over it? And they continue the ultrasound, pointing and measuring and clicking while my heart is pounding in my chest, and I'm trying to be calm because I want to be smart and aware and not pass out. Then they're finished and they ask me whether anyone is with me. Like I said, not good.

So, never, *ever* go to your mammogram alone. In fact, starting now, don't go to *any* doctors alone if you can help it. Obviously you can't always have someone with you, but it's really helpful when someone else is there. Sometimes there's just so much information that it's great to have another set of ears in the room—particularly if they can take notes for you to look at later.

I was lucky that my husband, Richard, had decided to come with me when I went for my mammogram. I wasn't even sure why he'd wanted to come, to be honest, but later he told me that when he felt the lump, he was worried, so he thought he'd better be there. So they bring him in, and

I'm sitting up now in my gown, kind of shaking, and he holds on to me, and the doctor says that he's going to say some things, and we'll probably forget almost everything we hear. My husband says, "Come on, we won't." The doctor looks at us sympathetically and says there are actually two lumps in my right breast, and we won't know for sure unless they do a core biopsy, but there's cause for concern. Now I'm shaking like a leaf, but I am completely aware of everything that he's saying. In fact I say, "Ignore the fact that I'm shaking. I understand everything you're saying." My husband is holding me by the shoulders, and we're staring at each other, and we're listening while he tells us they can do the biopsy now, or we can wait and make an appointment with a breast surgeon and then they'll order it. We agree that there's no time to waste—we're assuming it's cancer, right? The sooner you start doing the stuff, the better.

So they numb my breast as best they can, and then they stick in this giant needle with a kind of sucking thing on it, and they dig it deep into my breast, because that's where the lumps are, and it hurts like hell. They keep telling me they're sorry that it hurts, but it's really deep. And my husband is standing outside now, because this is not something he should see, and when they ask him to come back, I've got an ice pack on my boob, and I'm really shaking. They give us business cards for two breast surgeons and tell us we should call them on Monday. Of course it's Friday evening now. We walk out of the office stunned, a little numb, and I'm in serious pain.

We keep saying, "Let's not get ahead of ourselves. We won't know anything for sure until we get the results," but it was just so obvious from the way they were talking that it wasn't going to be good news. I was shocked. Floored actually. I mean, I was forty-one and had no risk factors. My grandmother had died of breast cancer at seventy-six, but every doctor told me that didn't count. My mother was fine, and I was forty-one! I didn't smoke, I had breast-fed my kids, I wasn't overweight, I ate well, I exercised. Sure, I was a chocoholic and probably drank too much Diet Coke, but breast cancer? No way!

One of my friends knew I was having a mammogram and got nervous when I didn't call her back after a few hours. She assumed the worst and called her neighbor, who happened to be an excellent oncologist. She told my friend I should call her in the morning. She turned out to be a lifesaver—literally.

So now it's Friday evening, and we're pretty sure I have breast cancer. The nurse and radiologist just looked so severe and serious it was hard to imagine it was going to be good news. We don't say anything to our teenage kids, because we don't know what to say, and we try to figure out what comes next. Who do we know? How do we find the right surgeon? What do we do first? I call the oncologist the next day and tell her what happened. She tells me it sounds like I'm not going to get good news, but this is a treatable disease and you have to take one step at a time.

This becomes a recurring theme. You will hear this over and over: Take one day at a time. Don't get ahead of yourself. Try to focus on the present. It's great advice, but certainly in those first few days and weeks, absolutely impossible to follow. You will learn how. You will find that as things go on, it's easier to do. Not every day—but some days.

In this book I'm going to tell you what I know from experience and from interviewing other women, nurses, and doctors. I'm going to give it to you straight and offer as much practical information and advice as I can. At the end of each section you'll find my Top 5 lists. These are the five things I think are vital to remember each step of the way. Here's my first Top 5, which is critical right now, almost immediately after you've heard the news:



1. ~~Don't panic. Well, you can panic a little, but not so much that you can't function.~~
2. Rally the troops. Think of anyone you know who might be able to help you navigate the next steps.
3. Breathe. This is just the beginning. You don't know much yet. Next come the tests and more tests. You can do this.
4. Stay away from the Internet. This is not the time to start researching everything that's ever been posted about breast cancer and all the statistics. The statistics are scary, and they don't apply to you yet. You don't know anything yet. Actually, this is good advice for the whole of your treatment: Stay away from random chat boards on the subject. They can freak you out unnecessarily.
5. Don't panic. Yup, worth saying again.

Tests

The next doctor you'll be referred to is either a surgeon or a medical oncologist. In most cases it will be a surgeon. This will be fine by you because right about now you're probably just thinking, *Get out!* Also, having an appointment with a medical oncologist before they have all the information that comes with surgery (type and size of tumor, positive or negative sentinel nodes, and so on) can be a little overwhelming, because without the lab results from surgery or biopsy it will be hard for them to prescribe the next step in treatment.

Regardless of whether you start with an oncologist or a breast surgeon—and I started with a breast oncologist, because that's whom I found first—after the core biopsies come the tests, and the waiting for results, and the question marks followed by more tests. Meanwhile, all you can think is—Just get it *out* already! I have cancer, and it's growing every day. Isn't it more likely to spread every day that I wait? The truth is that most breast cancers grow quite slowly, and the few days or weeks it takes to get all the tests done and everything scheduled don't increase the chances that it's spreading, but it is sure hard to sleep!

Let me say it now, and I'll repeat it later: The tests and the waiting are endless. This doesn't change. Ever. Once you've entered the Cancer Club, every visit starts with the waiting room. And no matter how little fun you're having, and how relieved you are to leave, it always takes too long to schedule the next visit, the next test, and it takes even longer to get the results. Or that's what it feels like, anyway.

I suggest you bring something to keep you busy while you're waiting; whether it's a friend or a loved one who can help you pass the time, work, or a book that you love, you're going to need something to help distract you from the whirling thoughts in your head. Do not rely on the waiting room magazines. The usual selection is more *Living with Cancer* than the latest *People*.

One of the things you'll have to think about is whom you should tell and how soon. I'll talk about that later. My husband and I chose not to say anything to anyone right away. We wanted to know what we were dealing with first.

MRI

Most likely your next test following the biopsy will be a breast MRI. Depending on where you live and what the scheduling is like, this can take anywhere from a day to a week or so to schedule. The MRI is used to determine how large the cancer is, whether there are any abnormal sites in the other breast, and also if there are any enlarged lymph nodes in the armpit that may signify that the cancer has spread.

An MRI uses a powerful magnetic field, radio frequency pulses, and a computer to produce

detailed pictures of organs, soft tissues, bone, and virtually all other internal body structures. The images will then be examined on a computer monitor by a radiologist, and the results sent to your doctor. You can, and should, also have the images copied onto a CD that you take with you and keep your records.

It wasn't my first MRI. I'd had ankle problems, and I'd been in the tube with all the knocking and clanging before. This one is different. First of all, when they were looking at my ankle, it wasn't a life-or-death situation. I wasn't lying there thinking about what it might mean. This MRI starts the same way. You go into the changing room and take off any and all metal you might be wearing, put on a gown, leave your stuff in a locker, and walk into the testing room, which they have to keep freezing cold because of the machine. That's where the similarities end.

The weirdest thing about a breast MRI is that you lie facedown, and there are these cups for your breasts. At least it doesn't hurt. You just lie there with your boobs hanging down for a while. I kept thinking of that song, "Let your boobs hang low, let them wobble to and fro . . . let your boobs hang low." You've got to do something to avoid thinking about the results of this test. Sing (silently), Dance (in your head). Recite the Declaration of Independence. Do anything you can think of to distract yourself from the what-ifs. You'll need this advice for the multiple tests you'll be having for years to come.

The radiologists look at both breasts and your lymph nodes to see if anything lights up. Based on what they see in an MRI, they may order further testing. If they think there may be lymph node involvement, they'll order other tests. Including more biopsies. Yup, more needles.

I had a lymph biopsy after my MRI. It meant they were worried that the cancer (which, by the way, they hadn't yet told me was cancer) had spread. For me, at least, it wasn't as painful as the breast core biopsy, although it's the same process, this time under my arm. First they stick a needle in the armpit and shoot lidocaine in to numb it. Then they stick in that same kind of suction needle device they use in the first lump biopsy while the nurse shows them where to go with the ultrasound. They say the worst thing you know is code: "You're going to feel some pressure." It's code for "pain." The sensation is definitely pressure. Lots of pressure. In your armpit. This happens a few times. There's lots of talking between the doctor and the nurse, and everyone is nice and also matter-of-fact. Still—big, painted pink, ribbon-wearing cancer elephant in the room. Talk about *stress*!

TOP 5 TIPS FOR YOUR FIRST MRI



1. Ask for a copy of the scan when you check in, and tell them you'd like to take it with you. This advice goes beyond all your scans. It's incredibly important that you have a comprehensive set of your own records. You might have to change doctors or hospitals—or sometimes even the most reliable office can misplace things. And you (and everyone around you) will forget things. Always, always keep a copy of all your own records.
2. Have someone you trust bring you to the test and take you home. It can be emotionally draining as well as physically taxing.
3. Make sure to take off anything metal. Jewelry, zippers, anything. And take off your shoes, even though they may tell you that you don't have to. One time I left my flats on, and when they began to move me into the machine, my feet started to be pulled up toward my chest. I almost had to yell for them to stop. There must have been metal inside the little heels on my shoes.

4. Relax. After this you'll still have to wait for the doctor's appointment before you get the results.
5. Ice is your friend. Use it. Biopsy needles are invasive, and they can damage the tissues they pass through. Ice reduces swelling. After any biopsy, as soon as you get home, apply ice—twenty minutes on, twenty minutes off for an hour, and then again after a few hours if it still hurts. Remember always to cover the ice pack with something. Do not apply it directly to the skin. Take ibuprofen if the site is sore.

PET SCAN

I call this the “PREP” scan because there's a lot you have to do to prepare for it. Officially, though, is a Positron-Emission Tomography/Computed Tomography (PET/CT) scan. It is used to produce images that pinpoint the location of abnormal metabolic activity within the body. First you will probably be asked to follow dietary restrictions for a day or so, depriving yourself of sugar and carbohydrates for twenty-four hours. This is because cancer cells grow quickly and require a lot of glucose. Limiting your intake of glucose before the test allows the scanner to detect any cells that are emitting signs of high glucose use when you're administered glucose during the test. Then you have to drink two huge bottles of this liquid, which is a type of barium “milk.” Notice the quotation marks. It looks milk-like, but it's actually chalk-like. Usually you drink one at home and one at the test center. It's no big deal. And it's really not that bad. Mocha is one choice, but don't be fooled: It's not your usual from Starbucks. I've had quite a few scans, and I've tasted all but banana. Mocha is the best—of course that's not saying much. I recommend using a straw to drink the stuff. It makes it go down a little easier.

This is the only test with audience participation. Every doctor's pretest instructions are a little different, but they all involve starting with some sort of clear-liquid diet and low-carb eating, because they want to make sure your cells are stimulated in a specific way during the test itself. You will most likely also be asked to refrain from strenuous exercise the day before the test. (Oh damn!) Next is the chalky drink, and then there's an injection of sugar containing radioactive FDG—fluorodeoxyglucose. The injection is through a line they start in your arm. Just a needle prick, not a huge event. The doctors are checking to see how the cells metabolize the sugar in the injection. During the scan the cells are active, and the activity shows up as bright lights on the images. The radiologist is looking for cells that appear abnormally bright. A PET scan may be ordered to look for signs of cancer that were not detected on an MRI or a mammogram.

My favorite part? After they've completed all the prep, they leave you alone and tell you to relax. This time they really mean “Relax.” A darkened room, no reading, no TV. Just you and your thoughts. My test center has a light-up photo of a beach on the wall. The tech turns it on as he leaves, and the water looks like it's moving. All of a sudden, amid the crashing waves, you hear the sound of seagulls calling. I kid you not. The worst part is that the first time I was there, I couldn't figure out how to turn it off. Not exactly soothing. It doesn't work anymore. *Such* a shame (I swear I didn't do it)!

Next stop, the PET room itself. It looks just like the MRI room. Once you're all positioned, and they leave the room and slide you in, you'll hear a recorded voice that tells you when to breathe and when to hold it. “Breathe in. Hold . . .” An hour or so later, “Breathe out.” Okay, it's not really an hour. I have no idea how long you actually hold your breath, but they tell you to do the best you can. I decided to turn it into a game. The first time I didn't make it all the way, but after a while I got in

the groove. The trick is not to pass out. Then it's time for the pee-in-your-pants sensation. Yup, they tell you that when they send the liquid through your arm you may feel a warming sensation through your nether regions. It's a peculiar feeling, and maybe just a little bit funny. But other than that, the test is pretty much a nonevent in terms of its physical toll on you. Wondering about the results takes a whole other toll. This is most likely the first of many PET/CT scans you will have in your life. Post-treatment, these are the follow-up scans they perform regularly to see if the cancer has returned.

TOP 5 TIPS FOR PET/CT SCANS



1. Bring a Xanax (or equivalent antianxiety drug) with you, and take it with the “milk” if you're claustrophobic or anxious.
2. Pee before you start the test, but drink lots and lots of water after. I learned this trick when I had dry mouth for days after my first PET.
3. If you have a PowerPort (everything you ever wanted to know about PowerPorts is found in [The Port](#), ask them to use it for the injections. You may have to have it accessed first by a chemo nurse, but I'm a believer in using that thing every single chance I get.
4. Make sure you've asked a friend or family member to drive you home when it's over. There's nothing truly horrible about this test, and there's no chance of getting results on the spot, but it still takes a lot out of you. Some doctors suggest you stay away from people because you're radioactive, but this never made any sense to me. You're in a cancer center surrounded by people when you have the test to begin with. I guess it couldn't hurt to stay away from other cancer patients or pregnant women for about six hours if possible.
5. There are always snacks available for people who've just had these tests—usually a granola bar or something. Go for it. Eat them. You deserve it. Take one for the car.

BONE SCAN

A bone scan, also called bone scintigraphy, is an imaging test used to determine whether breast cancer has traveled to the bones. Your doctor may order one at initial diagnosis, to make sure your bones are healthy. He or she may also want to create baseline images that can be used for comparison at a later date after treatment. Additionally, a bone scan may be ordered if you have bone and joint pain or a blood test suggests the possibility that the breast cancer has traveled to the bone. In other words, lots of reasons. Always feel free to ask your doctor why this, and any other scan, was or was not ordered.

This one is easy, even for me, and I'm claustrophobic. First they inject a radioactive material into your vein or through your port. They show up with the stuff in this strange metal cylinder, like mininuke, and then draw it up through a needle. Totally sci-fi. Then you wait an hour for the material to circulate. You don't feel different, and you don't start to glow. After an hour you lie down, and they slide you in and out of yet another tube-like machine. There's no pain, nothing disgusting to drink. It's just dull. The only side effect may be a metallic taste that some people get when they inject the material. Yup, I had that too.

TOP 5 TIPS FOR A BONE SCAN



1. Bring a Tic Tac or hard candy to suck on when they do the injection. It keeps the metallic taste away.
2. Bring a buddy, a book, or your own magazine. You really do have to sit around for at least an hour between the injection and the test. And the waiting room will most likely be filled with old magazines with “what’s hot” lists from the year before.
3. Practice relaxation breathing while you’re doing the test. There’s nothing else to do, and it gives you something to focus on.
4. Don’t be polite. If you hate country music, ask them to change the station! Believe me, once you’re stuck in there you’ll be sorry if you hate “Achy Breaky Heart” and you’re listening to it for the third time.
5. Again, pee right before you go in for the test. You’re going to thank me for this.

Usually the people who administer these tests are incredibly nice. They ask if you need a blanket or a pillow or anything else. If you can think of something that will make you more comfortable, let them know. If you don’t like the technician, ask to see someone else. Seriously. This is not the time to be accommodating.

Results

So of course you're hoping it's just the one thing. Just the tumor (or the tumors, in my case). You're praying that no lymph nodes are involved, that it hasn't spread. It's pretty much all you can think about during the tests. My brother is a radiologist, and he says the thing about these tests is that sometimes they can answer questions, and sometimes they create more questions. Lots of things show up on bone scans and PET scans that are not cancer, and sometimes you never find out what those things are. They're anomalies in your body, and they might be perfectly normal, but now you have to worry about them. The doctors see three "somethings" on one scan that they can't explain, so you have a different scan and it eliminates two of the spots. But there's a third, and they don't know what it is, but it doesn't look like cancer. This is exactly what happened to me. My results answered some questions and raised a few more. What was the third spot? Nobody knew. My oncologist said, "We've taken that road as far as we can; now we have to turn to what we do know. This is medicine. You have to accept some question marks." They don't know everything. It's really hard to live with, but true.

At this point you'll want to know what stage of cancer you're in, but if you're having surgery, the doctors won't give you a stage until afterward. They will talk to you about it, though, and the stages are both more complicated and less meaningful than I thought. What your doctor says to you about your cancer is more important than the stage number.

What you need to know right away is that *all* stages are treatable. Some stages come with surgery, chemotherapy, and radiation, some with only one or two of them. But *every* stage is treatable—even stage 4.

The literature now refers to breast cancer as a chronic disease. Something you can live with for a long time. This is true. I met lots of people in waiting rooms who'd been diagnosed ten, fifteen years before. I found this both encouraging and scary. I was happy to know I wasn't going to die right away, but I really couldn't imagine going through treatment for fifteen years. I guess you do what you have to do.

I do take offense, however, when it's referred to as a chronic disease like diabetes or something similar. Cancer is not like any other disease. It includes, among other things, a huge "dread" factor that most other chronic diseases don't have, and the treatments are not like those for diabetes at all. But you can live with it—many, many people *are* living with it—and there are new trials and drugs, literally all the time.

TELLING YOUR FAMILY AND FRIENDS

At the time my husband and I went to see one of the breast surgeons for a consultation, we still hadn't told our kids. I'd known for about ten days and had had a week of tests, but since the surgery hadn't been scheduled, we still hadn't said anything. The surgeon told us we had to tell them. Right away. He said that kids are sensitive, and they'd probably already figured out that something was up. We talked

to a social worker, read the pamphlets about how to tell teenagers, and found out we agreed with the consensus. Here it is: Be honest, but put it in a positive light. Mom has been diagnosed with breast cancer, but we're treating it right away. We're lining up a great team of doctors, and although it's scary, this is a treatable disease, and we're doing everything we can to make sure she's going to be okay. And we're going to tell you everything as we go along.

We followed the professional advice we received. We were honest and only offered as much detail as each child requested. Obviously everyone's kids will take the news differently. The social worker said that most will ask a few questions, then pretty much ask what's for dinner. This turned out to be true. My kids reacted according to their personalities. One only wanted the worst-case scenario: "Are you going to die?" The other wanted much more information. One moved on from the news quicker than the other. My daughter, Marisa, jokingly offers the following advice for what to do when you sit your kids down:

Step 1—Here's a cookie.

Step 2—I have cancer, but I'm going to be okay.

Step 3—Here's some money.

Since we had teenagers, we also told them not to search the Internet randomly because there's so much false information. Also, there'd be plenty of information out there that wouldn't apply to me. My son, Jeremy, would occasionally ignore my advice not to research things online, and then get upset by what he found. My daughter only cared about what was actually happening to me, not the statistics. My oncologist recommended that we tell them about www.breastcancer.org if they asked. It has the most up-to-date and scientifically sound information. That's what we did.

Telling the rest of my family was the worst part. There's never a good time to tell someone who loves you that you have cancer. My big worry was that my mother would want to move into my house. That's exactly what she wanted to do. We had to find a balance between her need to take care of me, my need still to be a grown-up, and my husband's need for some privacy. It turns out you have a lot of responsibility when you have cancer. How you present yourself and your disease to your family, friends, and coworkers is often complicated. Of course I wanted to be like the women in those *TV miniseries* who are fighters and deal with all the treatment and surgery with humor and grace. *Half* That's fiction. You know how you tell your kids that the monsters in the movies aren't real? Guess what? The perfect cancer patient in the movie isn't real either. The producers don't show her awake at four a.m., unable to sleep because of pain and side effects and worry. They don't show her yelling at the kids because of steroid rage. So don't set yourself or your family up. Be honest; don't oversell.

This book actually started as a blog on www.caringbridge.org as a way for me to let everyone outside my immediate circle know how I was doing. I did it partly as a way to cut down on having to tell the story a million times. Or receiving a hundred phone calls a day that started with, "Hi, just checking in to see how you are." I realized very quickly into my deep dive down the rabbit hole that I couldn't handle that.

When you tell people, they'll all respond differently. Some will tell you you'll be fine because you're young and strong. Or old and strong. Or just you. Some will burst into tears. Some will be stoic and offer to do anything they can for you. Some will immediately start talking about people they've known who've had cancer. Some will want to tell you horror stories. And then the advice starts. Some people just *have* to offer advice. A flood of advice. And all of it conflicting. About what you should or shouldn't eat or which doctor to see. About whether or not you should exercise. About how to keep

your spirits up (you will hear the words “fighting spirit” way too many times). They cannot help themselves.

If you’re like me, you’ll find some of it thoughtful and well intentioned but frustrating and confusing. And you’ll want to turn off the spigot. My surgeon’s nurse gave me the best advice of all. She told me just to say, “Thank you, but everyone’s experience is different, and I’m not comfortable talking about it.” For those who want to give you a medical consult, just say, “I’m very comfortable with my doctors, and I’m taking medical advice only from them, but thank you anyway.”

Not long after I was in treatment, a woman I had known casually for years and who I knew had been fighting her own battle for all that time wrote me an e-mail that ended with “Welcome to my club.” I wrote back, “Your club *sucks*.”

SHARING THE NEWS



1. Tell your kids and immediate family right away. Be clear and concise. Keep the script simple. Plan what you’re going to say, rehearse it with yourself or someone you trust, and stick to it.
2. Sign up for www.caringbridge.org or one of the other Web sites offered by your local cancer center to use as a clearinghouse for information. Even if you yourself don’t use it to write, someone in your immediate circle can do it to keep everyone up-to-date. You can even include photos. I posted ones of me in all my different wigs.
3. Make sure everyone knows your policy on advice. Medical advice should come from your medical team *only*. No exceptions. My brother’s a radiologist, and even though he counts as a doctor, I wanted his advice to come through my own oncologist so I had him call my doctor first. Doctors only.
4. Do not answer the phone if you don’t want to. It’s not your responsibility to listen to everyone’s reactions when they find out. Let someone else give you the message: “Dina called; she sends her love.” You don’t need to listen to twenty minutes of . . . whatever. People say so many things—from the inspirational to the insufferable. Pick and choose carefully.
5. Don’t pretend to be something you’re not. You’re shocked. You’re sad and shaken and scared and lots of other s words. You will be lots of other letters as well. You don’t have to make believe you’re okay with breast cancer. Of course you’re going to fight, blah, blah, blah. You got this book, didn’t you? Embrace the fact that your life may stink right now and you don’t have to pretend otherwise.

CHOOSING A SURGEON

The most important thing about choosing the right surgeon is knowing his or her level of experience with breast surgery. If possible, choose someone who only does breast surgery. Breast surgery, like all surgeries, is part science, part art. Some of what’s done in the operating room is, simply, the surgeon’s call, based on how much what he sees in you corresponds to what he knows. You’ll want someone who has seen almost everything there is to see, done almost everything there is to do. Make sure you know your surgeon’s point of view as well. Yes, surgeons have a point of view. Is she known for breast conservation or for being aggressive? Be sure you know where the surgeon’s coming from so you can

determine if that view meshes with your own. If possible, get a second opinion from someone with a different frame of reference so you can make the choice that feels right to you.

When they remove the tumor, it's all about the margins, the buffer zone of healthy tissue they take out with the tumor to make sure they've got it all. You need someone who can not only recognize where the margins of the tumor are, but who is skilled and practiced enough to know how to take out just the right amount of tissue, no more, no less. In addition, some types of surgery require "sentinel node biopsies," where the surgeon takes out specific lymph nodes—sentinels are a kind of early warning system—to perform an on-the-spot test for signs of cancer. Your surgeon needs to be able to determine the right sentinel nodes in your case. With all this going on, you can see why experience is paramount.

Finally, make sure the pathology lab in your surgeon's hospital has a great reputation. These are the people who will be doing the tests that determine the type of tumor you have, as well as whether there is node involvement. If they don't have a great rep, you have two choices: (1) choose another surgeon; (2) have the lab results sent out for a second opinion.

Do your homework. Find out who the head of breast surgery is, and meet with him or her. Ask everyone who the best surgeons are, and meet with them. I asked the radiologist who did my MRI, my oncologist, my friends. Then we met the people they recommended and chose the one we were most comfortable with. This is one time in your life when reputation is key.

Keep in mind that there is an advantage to having your oncologist and breast surgeon in the same hospital. Hospitals have tumor boards that meet weekly, and they discuss the cancer cases. If your oncologist and your breast surgeon are affiliated with the same hospital, all your records are under the same roof, and they can easily get in touch with each other if they need to.

At the end of the day you have to feel comfortable with the hospital, the surgeon, and her staff. This does not mean you have to like her. You'll only have a few interactions with your surgeon, so her personality is far less important than the results of her work. This isn't *Gray's Anatomy*. This is your life. You just have to feel confident that she knows what she's doing.

I met with two surgeons before I picked one. They both had superior reputations, and they were both obviously highly skilled. One was like a breast surgeon rock star. (Wonder what *those* concert t-shirts would look like?!) He was such a star that he'd left the big hospital, wooed by a smaller place to build its reputation. Good for him, bad for my boob. I didn't like the smaller hospital. I was worried about the quality of his support. The staff in the operating room comes from the hospital, as do the people in intensive care. I wanted the best of both worlds. I chose the surgeon from my oncologist's hospital, the one who told us he was a truffle hunter on weekends. Why he told me this, I don't know, but for some reason it made a difference. In the end it really doesn't matter what they say until they say something that makes you more or less comfortable.

TOP 5 TIPS FOR CHOOSING A SURGEON



1. Being able to talk to a human being, not voice mail, goes a long way toward a positive experience. When you call your surgeon with a question, you want a person on the other end. My surgeon has two nurses on staff to answer patient questions. It was invaluable to know that I could always call and one of them would be there to talk to.
2. You will have about six weeks of aftercare with your surgeon, so you'd better feel comfortable with him or her. That still doesn't mean you have to like him or her. You need to

feel confident in the surgeon's education, skills, and knowledge. You should feel heard and treated like a human being. But at the end of the day you don't need to love your surgeon—just his work.

3. If the differences are negligible, or if you don't know how else to choose, pick the surgeon with the hospital where you feel the care is the best.
4. Research the reputation of the pathology lab in the hospital where your surgeon works. Ask other doctors, friends, relatives, and so on to learn what you can. If you hear something you don't like, ask the surgeon about it. The response may give you something to go on.
5. After you do the research and decide, stop fretting. Even if lots of other people talk about some other rock-star surgeon, it doesn't matter. You've done your homework and made the best choice for you.

Surgery

ONE LUMP OR TWO? AND OTHER AGONIZING CHOICES

Your diagnosis may give you some answers, but it can also lead to many more questions: Lumpectomy or mastectomy? Single or double? Reconstruction or prosthesis? Which surgeon? Oncologist? And so on and so on. . . . All of a sudden you're presented with life-altering choices. You will probably find yourself wondering: How am I supposed to make these decisions, and why am I the one being asked?

First of all, there's one overall reason that your doctor will ask you to make some of these choices: There's no compelling medical reason to choose one option over another. *Whaaat?* you may ask. You're telling me modern medicine doesn't have all the answers? It does not. When there's no medical reason to sway your doctor in one direction, the deciding factor turns out to be your own lifestyle choices.

Since my surgery and treatment, I have often revisited the literature and asked for more medical opinions on removing my left (and so far cancer-free) breast. All the specialists keep telling me the same thing: There's no medical reason for removing it, but it's up to you. So here I am, left (purposefully intended) with one breast and one scar and a drawer full of prostheses. Here's my opinion, for what it's worth: There are huge pros and cons no matter what your choice. Helpful, right?

On the one hand, I enjoy having sensation on the left side of my chest. The anxiety I feel about the cancer returning has nothing to do with that lonely breast over there. I would not feel any more secure about my future if it was removed because once you've seen the great and powerful Oz, you know you're not in Kansas anymore and this is no Technicolor dream you can wake up from. This is real. On the other hand, having one breast is something I'm always managing around. If I'm not wearing a prosthesis, I'm wearing a flowy shirt and scarf for camouflage. I wouldn't say I'm used to it after all this time, but I've learned to manage. Which leads to the next choice you will have to make:

RECONSTRUCTION

This is a big topic. I, unfortunately, was not a candidate for immediate reconstruction because of the radiation I had to receive. This happens to many women, but as far as I can tell, it's rarely discussed. Everyone just assumes that reconstruction is an option for everyone and that everybody does it. Not true. In 2007, 63 percent of women undergoing mastectomy opted for reconstruction.* That means there's a whopping 37 percent of us walking around with either one boob or none. For some it was a choice. For others there was no choice. Either radiation caused too much tissue damage, or continued medications inhibit healing, or many other reasons. So if you're like me, and reconstruction wasn't on your list of menu choices, don't worry—you are not alone.

If, on the other hand, you have the option of reconstruction—lucky you? Yes, that question mark is there on purpose. You get more choices: (1) autologous reconstruction (using tissue from your own

body); (2) implants; (3) stem cells and fat tissue. (I have plenty of fat and fat tissue, if anyone needs my help.) All these options have their risks and benefits, and if you have the option of starting the process during the mastectomy, those choices need to be made quickly.

If you don't have to have radiation following surgery, my advice is to talk to plastic surgeon about reconstruction *before* your mastectomy. There may be skin-sparing or nipple-sparing procedures that your surgeon should perform if you are having reconstruction soon after a mastectomy. You can have implants or expanders, skin grafts, and many other options, and you should discuss them all with your doctors. It may seem like a daunting task to have these conversations right at the very beginning but that's the time to do it. Get two or three opinions, talk to your breast surgeon for referrals, friends and the like. Make sure the plastic surgeons you talk to have specific experience with breast cancer reconstruction. This is not the time to consult with the Beverly Hills doc who specializes in double D.

If you're reading this book in the early stages of diagnosis, take a breath here and do the research. Make sure that you're totally comfortable with the plastic surgeon doing your reconstruction, and that he or she is experienced in breast reconstruction, not just breast augmentation surgery. This is not the same thing as a Beverly Hills housewife wanting a pair of new boobs for Christmas. I told my husband I didn't mind having my mastectomy in Seattle, but if I was getting a boob job, I was going to Los Angeles. We even drew pictures of what we thought boob jobs looked like across the country. I wanted grade-A California boobs, but it turns out that's not the best way to pick a surgeon.

Breast reconstruction is a surgical specialty. A lumpectomy or mastectomy creates an entirely different surgical landscape than just regular implants. Number one, you have to be prepared to accept some level of asymmetry. In fact, your breasts are asymmetrical now if they're natural, but you're probably used to them. Once you start focusing on redesigning them, you kind of want them to be perfect. However, reconstruction is an imperfect art. The outside world won't be able to see the imperfections, but you will.

They do *amazing* things with reconstruction these days. Create new nipples, tattoo a new areola, lift, reduce, enlarge. The results can be extremely realistic. All plastic surgeons have before-and-after pictures for you to peruse. Just think—you may be America's Next Topless Model!

TOP 5 TIPS FOR CHOOSING YOUR SURGERY



1. Research all your surgical and nonsurgical options. Be sure to ask about the timing option for everything.
2. Meet several plastic surgeons and look at all the photos. Make sure you know what you're getting.
3. Ask about nipple options. Will they save yours or tattoo one on? Look at all the photos of the tattoos. Ask about 3-D tattooing—yes, this is a real thing. Your surgeon may know someone who does this.
4. Don't let yourself feel pressured by the timing. It's a big decision, and although it may be an option to start reconstruction during the mastectomy surgery, you may not be ready to make that decision in the midst of fighting for your life. Do what feels best to you.
5. If you have a life partner, this can be a tricky conversation. Both of you need to look at the photos and make peace with your decision. Don't forget, though, no matter what decision you make, a reconstructed breast following a radical mastectomy has no feeling. Sometimes

women who have reconstruction using a flap have some small areas of feeling return after a while; for the most part it's for display purposes only.

BEFORE

How can I tell you how to prepare for one of the most dramatic changes of your life? The most annoying thing to me was that all the books, and even the surgeon and some survivors I met, kept telling me that the surgery was the easiest part. You have *got* to be kidding! Yes, I know it's relatively simple surgery, but it's my breast and you are cutting it off! I agree it's the shortest part of the experience, but it's not necessarily the easiest. You know your hair will grow back after chemo but your breasts don't grow back. Even if reconstruction is an option for you, things will never be the same. You *will* get used to the new you—but it will take time.

There are so many fears and questions. Simple fear of surgery, for one. Fear of pain and discomfort and scarring, for another. Then there's the whole idea that your body will forever be altered, and you can't help wondering what it will really look like. There's a whole lot of anxiety for you and for anyone who might see you naked. The books all say to discuss it openly. Easier said than done. Still, it's vital to be able to talk about it.

Everybody responds differently and needs different things, but I can tell you what I did. I decided to take some time to myself and try to put it all in perspective. I took two days to focus on what was going to happen to me. I drove to the beach and walked along the shore. I stood in front of the mirror with my hand covering my breast, trying to picture what it would look like. I looked at photos in books and online. I didn't want to be shocked when I saw myself. Look, it's still shocking and dramatic. You can't change that, but you can prepare yourself so you have some buffer against the shock. I tied my hair up in a scarf and tried to envision myself bald. I think it helped me to just take the time to get ready for the onslaught. You don't necessarily need two days, but you might need more than two hours. By yourself, just to come to terms.

DURING

The morning of surgery you and your loved ones are most likely going to be on emotional high alert. Feelings of dread and anxiety plagued me the night before and the morning of my surgery, and right up until they knocked me out in the operating room. Any surgery is a little scary, this one even more so because *this* surgery has that big “cancer” word attached to it. *This* surgery has the added component of determining your next course of treatment. *This* surgery might tell you if the cancer has spread or not. It's not like they're fixing something that's broken. You usually don't go into the hospital feeling perfectly fine, knowing that by the end of the day you'll feel lousy. *This* surgery is scary.

I went to the hospital with my husband and my parents. The kids went to school, and I went to surgery. It was a very peculiar feeling to say good-bye to them like it was a normal school day, and then get in the car and head to the hospital for the beginning of the most dramatic chapter of our lives. I was more than a little nervous. I knew I'd wake up minus a boob and plus a port. I'd tried to find out as much as I could, looking at lots of images online and trying to wrap my head around what was happening, but I had only the vaguest idea what that would look or feel like. Also, we knew that we'd find out about the tumor's characteristics and what stage I was, officially. It's a lot to take in. The nurse who did my prep work was a survivor, which helped. Not only that, but she told me she still had her port in, seven years later. She'd just never bothered to have it removed. I have to say that made me

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