A PATIENT’S GUIDE TO RECOVERY AFTER MASTECTOMY

Now What?

AMY CURRAN BAKER

with MARYBETH CURRAN BROWN and LINDA CURRAN
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With
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and

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Aunt Ruth and Aunt Joan

For Eric, Phoebe, and Claire Bear

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Foreword

Breast cancer remains a prevalent disease in the United States with approximately 240,000 cases diagnosed each year. It remains the most common form of cancer in women and the second leading cause of cancer death in women. Luckily, treatments for breast cancer have improved dramatically over the past two decades. With improved scientific advancements and better directed therapy, we have begun seeing a slow decline in breast cancer mortality since 1998.

Surgery remains a common treatment for all breast cancer patients; even with the advent of breast conserving surgeries (i.e., lumpectomy) in the 1980s, mastectomy remains an important surgical treatment for patients. There has even been an increase in the use of mastectomy during the past ten years due to improved surgical techniques such as skin sparing and nipple sparing procedures, as well as improved reconstructive options such as muscle preserving DIEP flaps and direct-to-implant reconstructions. The increased use of risk reduction or prophylactic mastectomies for high-risk women has also become increasingly more frequent since we have found one of the genetic links to both breast and ovarian cancers (BRCA genes). For these reasons, it has become even more important that a book such as this, a resource guide for women undergoing mastectomy, be available.

We can tell you that, as surgeons specializing in breast surgery and reconstruction, we always receive questions from patients both before and after mastectomy regarding their limitations, recovery time, exercise routines, pain control, and after care. Given the ever-expanding amount of knowledge doctors have obtained in the treatment of breast cancer, we as physicians have found it more difficult to condense our discussions into easily understood presentations that can be fully grasped by all patients. The use of visual
tools has been very helpful but still does not portray the full psychological or physical impact from the surgery, which can be very variable depending upon the individual patient. To guide patients through these variable aspects of breast cancer surgical treatment and recovery, Amy Curran Baker and her sisters MaryBeth and Linda have created a really great resource for patients that will help patients both before and after surgery and significantly aid in their recoveries. And who better than two nurses and an occupational therapist, two of whom have themselves experienced mastectomies, to help patients learn from their own stories of recovery.

The authors have addressed both the psychological and physical aspects of mastectomy and also the reconstructive process. They write the book from a patient’s perspective, adding personal stories as well as expert occupational therapy advice, which are often not well covered by physicians in their zeal to help the patient understand all the factual medical information. In an age where information is so readily available through electronic sources yet is often misunderstood or even misinterpreted, it is refreshing to see a well-written resource that condenses factually referenced information into a form that a patient can understand and continually refer to for advice.

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Introduction

This year thousands of women in the United States diagnosed with breast cancer will undergo mastectomy. Many more will choose to undergo prophylactic mastectomy because they have a significant risk of developing breast cancer at some point in their lifetimes.

In 2008, I was one of these women. At age 39, I was diagnosed with invasive ductal cancer. I opted for bilateral mastectomy with direct to implant reconstruction. I have two children, a busy life, and a long family history of breast cancer. I knew what I wanted to do and I couldn’t wait to do it.

Within one month of being diagnosed I had my mastectomy and was on the road to recovery. But after the surgery I had a lot of questions: What about these drains? Why am I so tired all the time? Should I worry about lymphedema? As an occupational therapist who is trained to help people become as independent as possible in the face of a variety of disabilities and post-surgical conditions, I knew some of the answers from my own clinical training and experience. But a surprising amount of information came from speaking with other women who had gone through what I was going through, visiting on-line message boards, and when I couldn’t find the answers – just plain winging it. I remember wishing there was a book, a resource for all of the information I needed. Nothing fancy, just the basics . . .

So three years later – and feeling better than ever – I decided to create such a resource. I have enlisted two of my sisters, MaryBeth, a seasoned registered nurse, and Linda, a women’s health nurse practitioner and mastectomy patient herself, to help me with some of the nursing-oriented topics. We have included information on the key issues that post-mastectomy and reconstruction patients will encounter and need to know about: preparing for surgery, what to expect when you awake after surgery, the first few days in the
hospital, drain management, dressing and bathing, scar massage, lymphedema prevention, and more. We have compiled all of these topics together into this easy-to-read volume.

If you are reading this book, chances are that you or someone you know is considering mastectomy. Much of what you will read here will apply to all mastectomy patients, whether choosing to undergo reconstruction or not. Everyone’s experience will differ slightly depending upon individual choices and circumstances. With this in mind, I have shared my own mastectomy experience and I have enlisted the help of over 50 other mastectomy “veterans” who have responded to surveys about their own mastectomy and reconstruction experiences. They have all graciously agreed to share their advice and stories with you. Perhaps you will relate to their experiences in a way that will help you feel less alone during a very daunting and overwhelming process.

I hope that surgical oncologists and plastic surgeons will share this book with their mastectomy patients at a pre-operative visit so that their patients can refer to it throughout the process of preparing for and recovering from mastectomy. And once its usefulness has ceased, I hope that patients will pass it along to friends and family members who may be preparing for their own journey through mastectomy.

Amy Curran Baker
Acknowledgments

There are a great many people who have had a hand in creating this book and ushering it through to completion. First and foremost, I want to thank the women of FORCE and Support Connection. They are the mastectomy “veterans” who responded to our surveys, offered their advice for recovery, and generously shared their mastectomy experiences and stories so that – going forward – other women would have the answers they need. Thanks in particular to Sue Friedman, DVM, Executive Director of Facing Our Risk of Cancer Empowered, for allowing access to the FORCE message boards and for creating such a wonderful support community in FORCE.

I would also like to thank Sara Cohen, OTR/L, CLT-LANA, Memorial Sloan-Kettering Cancer Center. Sara offered her expertise and contributions for the Lymphedema Prevention section and provided much needed answers for the Rehabilitation After Breast Surgery section of the book. Thanks also to Holly Cline and Kim Dell of Amoena International for providing input on the Breast Prosthesis portion of the book. Thanks to Heidi Moncrief and Gabriel Rudow of Healthwise, Inc., for providing the breast reconstruction medical illustrations. Thanks also to the organizations that allowed permission for important mastectomy related information to be reprinted including: The American Cancer Society, The National Lymphedema Network, UCSF Breast Care Center Website, and The American Board for Certification in Orthotics, Prosthetics, and Pedorthics.

Other friends, colleagues, and physicians who reviewed the book, offered comments and expertise, and cheered me on along the way include Sharon Smith, MA, OTR/L, S. Lynn Karidis, PT, owner of Breast Cancer Rehabilitation of Westchester, and Tina Coyle, MS, NCC, LPC, Peer Counselor, Support Connection. Also, I
would like to thank my fabulous medical team including Andrew Ashikari, MD, C. Andrew Salzberg, MD, and Elizabeth Chabner Thompson, MD, MPH, all talented physicians and genuinely kind, caring individuals who offered their feedback and medical expertise in reviewing the manuscript.

Thanks to Noreen Henson, Editor at Demos Health, for believing that this project was important and recognizing that it would ultimately help many women faced with the prospect of mastectomy. My appreciation also goes to Joanne Jay and Tom Hastings at Demos for their tireless efforts in bringing *Now What?* to completion.

Thanks to my sisters and co-authors, MaryBeth Curran Brown and Linda Curran, for the their ongoing contributions, editing, reviewing, expertise, encouragement, and putting up with me! Finally, thank you to all of the members of my family, including my parents Thomas and Nancy Curran, my “big” sisters MaryBeth, Jennifer, and Linda, my in-laws Nancy and Ralph Baker, my husband Eric, and my daughters Phoebe and Claire for their love, support, and patience these many months.
Making the Difficult Decisions

If you are considering a mastectomy because you have been diagnosed with breast cancer or you are contemplating *prophylactic mastectomy* due to heightened hereditary risk, you have come to the right source. This book is about planning for and recovering from mastectomy. If you are in the early stages of decision making and haven’t yet decided about having a mastectomy, you should know that there are some wonderful resources out there to help guide you through your decision-making process. There is an extensive resource section at the back of this book to help with this decision. Note that much of the planning and recovery from your mastectomy procedure is related to the type of procedure that you ultimately select.

**My Story**

Each of us has her own reason for making the decision to have a mastectomy. For some women, mastectomy is one of several possible treatment options. For others, mastectomy may be the only option. Overall, however, my situation and decision-making process may have been a little different than most. I was 39 years old with two kids and a significant family history of breast cancer. My mother, my maternal grandmother, and my maternal Aunt Ruth had all been diagnosed. My mother had been diagnosed in her 50s, my grandmother in her 80s, and my Aunt Ruth in her late 30s. And here I was,
almost 40 years old and I had only been for one mammogram so far. What I know now is that with my family history, I should have been getting a yearly mammogram and twice yearly breast exams beginning at age 35. I had my first mammogram at age 32 when I thought I felt a lump. My wonderful OB/GYN at the time, who had seen me through the birth of my first child, felt it too, and another lump besides. She immediately sent me for a mammogram that, thankfully, came back normal.

So there I was seven years later. Life was busy and I was in the trenches of parenting two wonderfully spirited young girls. I was muddling along, in full denial of the fact that I have a real risk of breast cancer and should go for another mammogram. Actually, I wasn't in full denial. I had made several appointments — and I had canceled several appointments. Once I even actually showed up for my appointment only to be turned away because I didn't have the necessary referral. I did a monthly self-exam in the shower but sometimes I didn't really know what I was feeling. Looking back I may have felt a lump in my right breast but I was never exactly sure what I was feeling so I didn't pursue it — a bump here, a rib there. What was cancer going to feel like anyway?

So when my sister Linda springs it on me in late January of 2008 that she is planning on coming east from her home in Hawaii to undergo a bilateral prophylactic mastectomy, my jaw drops. But I try not to let her see my reaction because I want her to feel supported in what, undoubtedly, has to be one of the hardest decisions any person can make. To take essentially healthy breasts and opt to remove them — and in the process causing yourself pain, discomfort, and inconvenience — in order to reduce the risk of developing cancer down the line was, I felt, a decision that really took some guts. Linda had a history of atypical ductal hyperplasia, which basically means that there were some unusual cells growing in the milk ducts of her breasts. They weren't cancerous cells but they weren't typical cells either. Her physician and a genetic counselor had cautioned her that she had a significant risk, based on this diagnosis and family history, of developing breast cancer “at some point” in her lifetime.

Linda had it all planned out. She had done the research and found a small hospital that was doing really cutting-edge work in the areas of mastectomy and breast reconstruction. Coincidentally, the hospital
just happened to be about 30 minutes from my house in New York. So she would fly from Hawaii with her husband and baby daughter, have the surgery, and then come to my house to recuperate for two weeks or so afterward.

I sat in the waiting room with Mike, Linda’s husband, and held their beautiful seven-month-old baby girl while Linda underwent a bilateral prophylactic mastectomy with direct to implant reconstruction, popularly known as one-step surgery. The surgery went beautifully and her physicians, a surgical oncologist and a plastic surgeon, met us in the waiting room with broad smiles and positive reports — the initial pathology was all clear; that is, no cancer had been found.

Two days later Linda was discharged from the hospital. But before we left the hospital, I decided that the least I could do was go to the breast center and set myself up for a mammogram. I mean, look at how proactive Linda was being and here I was burying my head in the sand still. So I booked it.

Linda’s recovery went well. Two days after discharge, drains and bandages neatly concealed, she was feeling well enough to enjoy Super Bowl Sunday at a local hotel bar while sipping on a Shirley Temple. Nine days after surgery she flew home to Hawaii with a newfound peace of mind.

And that is where my story really picks up. In late February I went for that mammogram. I was nervous as hell. They took the pictures and then told me to wait for the results. I waited a long time before they finally sent me home but I was nervous because I had a feeling something was wrong. That night my primary care physician called me to say that they found something and they wanted me to come back for additional views. “What we might be looking at here is invasive ductal cancer,” she said. I'm pretty sure that I almost died right then. I went back the next morning and the mammogram technician took additional images. The radiologist called me in and showed me the picture of my right breast blown up to the size of my head. There were some red pen marks circling the “problem” areas.

I don’t think I ate or slept much for the next few weeks. I did cry a lot, though. I allowed myself only once to go “there.” You know the place. The place where I am not here to take care of my two girls, who at the time were ages three and eight. I was seen a week or so later by my sister’s surgical oncologist, now my surgical oncologist,
too. I almost passed out in the examination room when he told me that, given my family history, he thought there was at least a 50:50 chance that this was cancer. Looking back now, I think he was being careful with his estimate, probably in an effort to help me keep it together enough to make it through that appointment. I have since learned that when you have a mammogram, your radiologist assigns something called a BI-RADS score to your images. BI-RADS stands for *Breast Imaging-Reporting and Data Systems*, it is a rating scale of 1 to 6. Each number corresponds with a description of what has been found on a mammogram. A number 1 means the mammogram is all clear for cancer. A number 6 means that your cancer has already been confirmed by biopsy and now they are just imaging it for treatment purposes. I earned a BI-RADS score of 5, which meant that there was about a 95 percent chance that my mammogram was positive for breast cancer.

My physician referred me to an affiliated hospital for a biopsy. The results came back as *DCIS (ductal carcinoma in situ)* Stage 0 cancer. I was both shocked and elated — shocked that at age 39 I would be diagnosed with breast cancer of any kind; elated that, after weeks of worrying, my cancer was found to be Stage 0, which meant that it hadn’t spread beyond the milk ducts into the surrounding breast tissue. Maybe I had gotten lucky.

And that’s where this book comes in. I quickly decided that I, too, would undergo a bilateral mastectomy with immediate reconstruction. I was lucky because Linda’s experience had not only prompted me to act but also paved the way for me.

Honestly, I didn’t really think, I just acted. I had met the surgeons, been to the hospital, and knew enough about the process to anticipate what my recovery would be like. And once I had locked into a plan it made me crazy to have people trying to talk me out of it — they always seemed to be pushing for me to get a *lumpectomy*, which is when the surgeon removes just the cancer and a bit of the normal surrounding tissue from your breast. Lumpectomies are a good option because they allow the surgeon to preserve the breast to the greatest extent possible. But I wanted a mastectomy, that much I knew for sure. I had spoken at length with my physicians about the decision I was making and I wanted some reassurance that my hereditary lot in life was not going to sneak up on me again and catch me by surprise when I least expected it.
I decided that my left breast, the non-cancerous breast, would undergo a prophylactic skin sparing, nipple-sparing mastectomy with direct to implant reconstruction. That’s a lot of fancy lingo for: They saved the nipple and the skin covering my breast but they took out the breast tissue and inserted an implant under my pectoralis major muscle. Because I didn’t have cancer on that side, this surgery was considered “prophylactic”; in other words, it was an opportunity to head off cancer from developing in that area in the future. There are many reasons for having the surgery done bilaterally (on both sides). Besides the obvious health reason I just mentioned, it is also easier for a plastic surgeon to achieve symmetry of the breasts if both sides are being reconstructed.

My right breast, the cancer side, underwent a skin-sparing mastectomy with the same type of implant reconstruction. They kept most of my skin so it was considered “skin sparing” but my surgeon felt that the cancer was too close to the nipple to be safe. So the nipple would not be spared. I didn't mind. Later on, several months after I had healed from my initial surgery, my plastic surgeon would fashion a nipple for me through some sort of origami-like technique using my own skin and the surrounding scar tissue. Finally, they would finish the job with a tattoo that would leave me with a reasonable facsimile of a real nipple.

I remember the frustration I felt at not having the mastectomy sooner. I wanted to fast track the whole thing. I wanted those things off yesterday. But I would have to settle for having the surgery a month or so after my diagnosis on April 16, 2008. I knew that the recovery process was not simple but it wasn’t awful either. I had watched my sister’s recovery and I was a rehabilitation professional myself, so I had those things going for me. But I still felt there was a lot of information I just didn’t know. I turned to the Facing our Risk of Cancer Empowered (FORCE) on-line message boards on a daily basis. FORCE is a non-profit organization devoted to providing support to women with increased familial risk for breast and ovarian cancer. Many of these women have tested positive for the BRCA 1 or 2 genes. People who are BRCA 1 or 2 positive carry a gene that puts them at significantly increased risk for breast and ovarian cancer. I tested “negative” for the BRCA gene but, as my physician explained to me, there is a whole population of women like me out there who have strong family histories of breast cancer
yet test BRCA negative. This may simply be because we carry a gene mutation that researchers haven’t discovered yet. The women posting on the FORCE board were an excellent source of information about hereditary breast cancer, options available for surveillance and treatment, and various post-mastectomy recovery issues. And they were so supportive that I couldn’t help but feel at home there.

When I went back for my pathology results a week after the surgery, I was surprised to learn that my breast cancer had been invasive. Although the small biopsied area had only shown DCIS or Stage 0 cancer, there was also a small area of invasive cancer as well as other areas of DCIS and cancer extending into the lobules. So in the end, I would undergo adjuvant chemotherapy. The chemotherapy, along with my mastectomy, and later the oral medication tamoxifen, would give me the added insurance I needed that my cancer wasn’t coming back. And as far as I was concerned, the mastectomy had been the best choice for me and the pathology results confirmed it. I was happy with how I looked reconstruction-wise and I hadn’t really had too much pain. Discomfort, yes, but full on pain, not so much of that really. And now I could rest easy that the cancer was gone and if I could just get over this next chemotherapy hurdle, life would go back to normal. And it did.

Surgical Options

My story complete, that bring us back to the whole decision-making process. Let’s begin with the surgical options. In the next few pages, I will provide a basic overview of the different types of breast surgery that your physician may recommend if you have been diagnosed with breast cancer or are considering prophylactic mastectomy. I will also review some of the reconstructive options that may be available to you. This is not an exhaustive list; for the most in-depth information on this topic, see Kathy Steligo’s classic, The Breast Reconstruction Guidebook, listed in the resources section at the back of this book. Her book is widely considered to be the most thorough resource on the topic of breast reconstruction options.
If you have been diagnosed with breast cancer, your surgeon may tell you that you have the option to have either a lumpectomy or a mastectomy. Here are some basics about each type of surgery.

**Lumpectomy**

With a lumpectomy, the surgeon removes the cancerous tumor and a small amount of healthy surrounding tissue. This surrounding tissue is referred to as the *margin*. Surgeons want to be sure that they get good or “clean” margins because then they can be reasonably assured that they have removed all of the cancerous tissue from the breast. The *nipple and areolar complex (NAC)* is typically not removed with this type of surgery. Usually *radiation therapy* is also prescribed as part of the treatment after lumpectomy. Lumpectomy is considered a *breast conserving surgery* because it allows the patient to keep most of her breast and there is typically less cosmetic impact. If margins are found to be positive after surgery, a *re-excision* may be required in order to remove all of the remaining cancer.\(^2\)

**Mastectomy**

If your surgeon advises that you are a candidate for mastectomy, you should be aware that there are several different types of mastectomy. Each type differs based on the amount of tissue that needs to be removed from the breast and the surrounding areas. Your breast surgeon will make a recommendation about what procedure is best for you based on your unique health circumstances. The different types of mastectomy are as follows:

- **Simple Mastectomy**: With this procedure the breast tissue and the NAC are removed but the underlying chest muscles and the axillary lymph nodes are left intact. This procedure is also called a *total mastectomy*.\(^3\)
- **Modified Radical Mastectomy**: This procedure involves removing all of the breast tissue, the nipple areolar complex, and the lower axillary lymph nodes.\(^4\)
■ **Skin Sparing Mastectomy:** This type of surgery removes the breast tissue but leaves most of the skin over the breast intact. The nipple and areola are also removed.

■ **Nipple Sparing Mastectomy:** With this procedure the underlying breast tissue is removed; however, the skin and nipple/areolar complex are preserved.

■ **Prophylactic Mastectomy:** This is when a patient undergoes mastectomy prior to receiving a cancer diagnosis. The procedure is a preventive or risk-reducing measure based on individual medical history, family history, or *BRCA* status.

■ **Radical Mastectomy:** The entire breast is removed as well as the skin, nipple, some or all of the underlying muscle tissue, and all of the axillary lymph nodes. This procedure is no longer performed as often as it once was due to advances in mastectomy technique and breast conserving surgeries.⁵

There are many variables for what makes each of us good candidates for one type of surgery over another. A nipple sparing mastectomy, for instance, is unlikely to be recommended if the cancerous tumor is large or located within two centimeters of the nipple. It also may not be recommended for women who are very large breasted or who have significant sagging of the breasts, also known as *ptosis*. A radical mastectomy may be the best choice when the tumor is large and the cancer has spread to the chest wall. Consult with your breast surgeon about what type of procedure is recommended for you.

### Lymph Node Removal

As well as surgical options, there should also be a discussion with your physician about lymph nodes. *Lymph nodes* are the small, bean-like structures that pick up and move lymph fluid through our bodies, returning it to the blood stream. Lymph is made up of water, bacteria, fat, and parts of white and red blood cells.⁶ If you have been diagnosed with breast cancer, whether or not the cancer has spread to your lymph nodes will help determine the *staging* of your cancer. *Axillary lymph node dissection (ALND)*, or removal of all or some of the lymph nodes in the underarm area, used to be routine practice when a woman was having a mastectomy. Today, techniques have
improved and are significantly less invasive. Your surgeon will most likely recommend a sentinel lymph node biopsy (SLNB) to determine if the cancer has progressed to your lymph nodes. In September of 2010, the National Surgical Adjuvant Breast and Bowel Project released a study confirming that women who underwent sentinel lymph node biopsy had the same survival rates after eight years as the women who underwent axillary lymph node dissection.\textsuperscript{7}

**Sentinel Lymph Node Mapping and Biopsy**

The sentinel lymph node is the node that the lymph fluid first encounters when exiting the affected breast. This node acts like a sentinel or “guard,” allowing fluid to pass to the other lymph nodes. There can be more than one sentinel node found and on average about two nodes are typically found. Through a process called sentinel lymph node mapping or lymphoscintigraphy, a radiologist or surgeon is able to determine the location of the sentinel lymph node(s). In this procedure, a radioisotope and/or blue dye is injected into the affected breast. The radiologist, during the lymphoscintigraphy, injects the radioisotope to determine the location of the sentinel lymph node(s) and marks it on the skin for the breast surgeon. The surgeon uses a gamma counter to identify the radioactive tracer during the surgery, thus identifying the first draining lymph node(s) of the breast. During the surgery, the surgeon may also inject a blue dye into the breast, which also drains into the sentinel node(s) and further enhances the identification of the sentinel node(s) by turning them blue. In these ways, the sentinel node(s) can be removed and checked for cancer. A sentinel lymph node biopsy is not usually recommended for prophylactic surgeries; however, some physicians will recommend it for women with a known genetic mutation. If the sentinel lymph node is cancer free, the reasonable assumption can be made that the next lymph nodes in the sequential chain will also be cancer free.\textsuperscript{8} This eliminates the need for removing more lymph nodes than absolutely necessary. A condition called lymphedema — a condition that occurs when a person’s lymphatic system does not drain lymph fluid properly — can occur when lymph nodes are removed, injured, or radiated so it is preferable to leave as many healthy lymph nodes intact as possible. After breast surgery with removal of lymph nodes, lymphedema
can occur in the arm and/or chest area and, because the lymph channels are altered, can cause swelling in those areas. It should be noted that sometimes lymph nodes tend to be in close proximity to each other so even though you may be having a sentinel lymph node biopsy, it is possible that more than one lymph node will be removed with this process.

**Axillary Lymph Node Dissection**

If the sentinel lymph node biopsy reveals that cancer is present, an axillary lymph node dissection may be performed. With axillary lymph node dissection there is a greater chance that a person will develop lymphedema; however, this largely depends upon the number of lymph nodes removed. The more lymph nodes removed, the greater the chance of developing lymphedema later on. That said, even with sentinel lymph node biopsy, which presumably only involves one or few lymph nodes, there is a small chance of lymphedema developing. See the section on Rehabilitation Questions and Answers and Lymphedema Prevention for more information about this topic. One important point to note is that once you have already undergone a mastectomy, a sentinel lymph node biopsy is no longer possible. The reason for this is that the tracer dye cannot be injected once the breast tissue has been removed. It makes it important, if there is a suspicion that cancer may have reached the lymph nodes, to take advantage of the sentinel lymph node biopsy at the time of the mastectomy in order to avoid axillary lymph node dissection at a later date.

**Reconstruction Options**

The next question: If you have chosen to have a mastectomy, do you want breast reconstruction? You should know that thanks to The Women’s Health and Cancer Rights Act of 1998 (WHCRA), health insurers that cover mastectomy must also offer coverage for reconstructive services and certain post-operative complications. Under WHCRA, a patient who has undergone a mastectomy is entitled to reconstruction of both the affected and unaffected breasts in an effort to create a balanced and natural appearance of the breasts. Prosthetic breast forms, lymphedema treatment, and treatment for other post-operative complications must also be
covered under this law. The United States Department of Labor and the American Cancer Society websites, which are listed in the Resources section of this book, both contain lots of information about WHCRA and include lists of frequently asked questions that may be helpful.

I’m proud to say that my home state of New York has taken this issue one step further and recently passed legislation that requires physicians to tell patients about their reconstructive options before performing any surgeries to remove cancer. The purpose of this law is to help women make informed choices about mastectomy, lumpectomy, and the various types of reconstruction that are available to them. When women are given this information early in the process, they are then likely to have all the necessary tools to make the most informed decisions they can about the options available. Hopefully other states will follow New York’s lead and adopt similar legislation in the future.

Most physicians’ offices will have a person on staff whose job it is to negotiate with your health insurance company to get your surgical procedure covered. If you decide that you want a specific type of procedure that is not covered within your network, you can apply for something called a “gap in coverage exception.” With adequate documentation from your physician, you may be successful in getting your insurance company to cover your procedure of choice.

To Reconstruct or Not to Reconstruct?

Sometimes women choose to have no breast reconstruction. Other times, women want or need to delay their breast reconstruction surgery. This may be the case if the woman has a long treatment road ahead of her consisting of radiation or chemotherapy, or if she wants to take it slow and examine all the options before making a decision about what type of reconstruction to pursue. Getting a breast cancer diagnosis in itself is such an overwhelming event that having to make a lot of decisions about reconstruction may be too much all at once. When I was diagnosed I didn’t know the first thing about breast reconstruction. If I hadn’t had the benefit of my sister’s experience, I probably would have chosen to delay my breast reconstruction to give myself a chance to explore all of the available options.
Implant and Flap Overview

If you ultimately decide on breast reconstruction, what type do you prefer: reconstruction with implants or reconstruction using your own tissue? When implants are used there are a couple of options: tissue expanders or direct to implant. With both types of surgery, the final result is that an implant is placed under the chest muscle and skin to form the breast mound. With autologous or “flap” procedures, the patient’s own tissue is used to form the breast mound. Here is a quick overview of some of the most frequently performed types of breast reconstruction as outlined by the American Cancer Society.11

Implant Options

Direct to Implant or One-Stage Immediate Breast Reconstruction
With direct to implant reconstruction both the mastectomy and the reconstruction are done within one surgical procedure. First, the breast tissue is removed by the breast surgeon and then the plastic surgeon takes over to place the implants. The implants are filled with saline or silicone, depending upon the type you and your surgeon have agreed upon ahead of time. Because there usually isn’t enough muscle tissue to cover the implant immediately, a tissue matrix like Alloderm™ may be used to form a pocket to hold the implant in place. The tissue matrix provides a foundation for your own tissue to grow. It acts something like scaffolding, covering the muscle and keeping the implant in place until your own tissue has grown enough to cover the area. This is a fairly new type of surgery that is gaining popularity because it is a relatively brief surgical procedure and recovery time tends to be short. Not every person is a candidate for this type of surgery, so check with your plastic surgeon about your specific situation.

Tissue Expander to Implant or Two-Stage Reconstruction
This is the traditional form of implant surgery. With this type of surgery the breast tissue is removed and then a tissue expander, like a balloon, is placed under the chest muscle. Over a period of
several months the expander is gradually filled with saline through a small valve until the skin and muscle have stretched adequately and the optimal breast size has been achieved. Later, a second surgery is performed to swap the temporary expander for a more permanent implant.

“Flap” or Autologous Tissue Options

With autologous or flap procedures, the patient’s own tissue is used to form the breast mound. Many people who do not want a foreign object such as an implant in their bodies choose this option. Whether or not you are a candidate for this type of surgery may depend upon how much fat or extra tissue you have in various areas of your body. The length of surgery and recovery period for flap procedures is typically longer than for implant surgeries. The American Cancer Society website outlines many of the most common types of flap procedure:

- With a deep inferior epigastric artery perforator flap, popularly known as a DIEP, the surgeon takes tissue, fat, small blood vessels, and skin from the abdomen and relocates it to the chest to form the breast mound. As with many of the autologous
procedures, this is microsurgery and there will be two surgical sites: the donor site from which the tissue is harvested and the reconstructed breast site. Using a special type of microscope, the surgeon reattaches the small blood vessels so that the transplanted tissue is viable. This procedure provides a “tummy tuck” because it removes tissue from the abdomen, just below the bikini line.

With the **transverse rectus abdominis muscle flap** procedure, also called a **TRAM**, there are two options: the **pedicle TRAM flap** or the **free TRAM flap**. With the pedicle TRAM flap, one of the rectus abdominis muscles of the abdomen is rerouted up under the skin to form the breast mound. The original blood supply is left intact. Mesh may be used to secure the area of the abdomen where the flap has been removed. With a free TRAM flap, the muscle, skin, blood vessels, and fat are removed from the donor site and reattached at the reconstruction site. This again requires the blood vessels to be reattached through microsurgery in order for the transplanted tissue to be viable.
The **latissimus dorsi flap** is a combination procedure that involves rerouting of the latissimus dorsi muscle of the back to form a pocket on the chest for a breast implant. Sometimes there is enough tissue to form the breast without using an implant.

With a **superior gluteal artery perforator flap** or **SGAP**, the gluteal muscles of the buttocks are used, along with skin, fat,
and blood vessels, to form the breast mound. This tissue is reat-tached with microsurgery.

Superior Gluteal Artery Perforator (SGAP) Flaps.
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Things to Consider

Each of us will want to consider various personal and health issues before making a decision about breast reconstruction. This is an important conversation that should take place between you and your physician. Variables that may impact your reconstruction options include your breast size, amount of ptosis, previously radiated skin, and amount of excess body fat. There are positives and negatives for each type of surgery listed here. For instance, with implants there is a good chance that you will need to have them replaced at some point in your lifetime. The lifespan of today’s generation of breast implants is roughly 10–15 years. Also, there continues to be some controversy surrounding the health impact of implants. The U.S. Food and Drug Administration devotes a full section on its website to the safety of breast implants. With autologous procedures, there are two surgical sites to care for and there is always a chance that the flap will not be viable or that there will be residual muscle weakness at the donor site.

I have seen amazing results from both implant and autologous reconstruction. Sometimes the results are so good that you would have difficulty believing that they are not the woman’s original breasts. It is important to know your surgeon’s level of experience with the procedure you want. Don’t be afraid to ask your plastic surgeon for references; there should be former patients who are
willing to speak with you and post-operative photos available to review — this is standard in the world of breast reconstruction. The following information has been printed with the permission of the U.S. Food and Drug Administration.

Questions to Ask Your Surgeon about Breast Reconstruction:\(^3\):

You may have additional questions as well.

1. What are all my options for breast reconstruction?
2. What are the risks and complications of each type of breast reconstruction surgery and how common are they?
3. What if my cancer recurs or occurs in the other breast?
4. Will reconstruction interfere with my cancer treatment?
5. How many steps are there in each procedure? What are they? How much experience do you have with each procedure? What is the estimated total cost of each procedure?
6. How long will it take to complete my reconstruction?
7. Do you have before and after photos I can look at for each procedure and what results are reasonable for me?
8. What will my scars look like?
9. What kind of changes in my breast can I expect over time?
10. What kind of changes in my breast can I expect with pregnancy?
11. What are my options if I am dissatisfied with the cosmetic outcome of my breast?
12. How much pain or discomfort will I feel and for how long?
13. How long will I be in the hospital? Will I need blood transfusions, and can I donate my own blood?
14. When will I be able to resume my normal activity (such as athletic activity, sexual activity)?\(^3\)

Choosing Not to Reconstruct

Many women choose not to reconstruct after mastectomy. In fact, it is estimated that 30–40% of women do not reconstruct.\(^4\) Whether
this is actually by choice or due to lack of information about the breast reconstruction options available, it represents a significant number of women. As with all of the decisions you will make surrounding mastectomy and breast reconstruction, choosing not to reconstruct is very personal. There are lots of reasons not to reconstruct. Eileen, for example, chose not to reconstruct because:

\[
\text{At the time I didn’t feel it was important to me. I looked at photos of mastectomies with no reconstruction and I was not bothered by the photos. I wanted the least amount of surgery and the easiest recovery.}
\]

Some women choose not to reconstruct because they want to take time to consider all of their options before rushing into a decision about reconstruction. Others want only one surgery and a quick recovery period so that they can get back to a normal life as soon as possible without having a lot of follow-up restrictions. Other women wait because their breast cancer treatment process is ongoing and may include radiation that can impact reconstruction options. Many women who ultimately opt not to undergo breast reconstruction report feelings of freedom and liberation at being “breast free” after mastectomy. And for other women, not having breasts is the end result of failed reconstruction. In this case, going without breasts is not really a choice and can be a devastating development. Regardless of the reason for not reconstructing, there are on-line forums such as Breastfree.org (www.breastfree.org) to support you before and after your mastectomy, and while you adjust to your new body.

Decisions

You should consider consulting with more than one breast surgeon and plastic surgeon before your final decisions about mastectomy and breast reconstruction are made. You should also talk to other patients about their decisions, recovery processes, and cosmetic results. Health insurance issues will also play a role in your decision-making process. Here’s some advice from a mastectomy veteran:
Read as much as you can, ask as many questions of the doctors as you can think of. Ask the surgeon to put you in touch with former patients who are willing to talk with you. Get on message boards and communicate with other women who have been there. ALWAYS get a second opinion. Even if there is no doubt about having the surgery, the different perspective of another doctor is very valuable. (Melanie)

As much as possible, take your time, examine your options, and make the decision that feels right for you. Once you feel confident in your decision, don’t let people with different opinions throw you off course. Undoubtedly, there will be people — family members, friends, and co-workers — who will not agree with your choice. This can be one of the hardest things to deal with when you are making these tough decisions.

As one who has been down this road, made these incredibly difficult decisions, and gone through this very foreign process myself a few years ago, I want to share with you some of the things I learned that may make your journey through recovery a little easier and, with hope, less frightening. I have also enlisted other mastectomy veterans to share stories of their own recovery experiences in the hope of easing your journey through and beyond mastectomy.