

FRANKLY
SPEAKING
ABOUT CANCER

Breast Reconstruction



SECOND EDITION

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in *their care* along with their health c
will improve the *quality* of their lives
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Prologue



When you hear the words, “you have breast cancer,” it’s easy to feel like you need to make decisions within days of your diagnosis. But in most cases you have time to meet with different physicians to learn about your surgical, treatment and reconstruction options. The Cancer Support Community taught me the importance of taking a proactive role in my decision-making and I encourage all women to do the same.

— Sharishta

No matter what your individual circumstances may be, the decision about whether or not to have breast reconstruction after cancer is tremendously difficult and it requires a great deal of thought.

Often, women diagnosed with breast cancer are asked to make a variety of decisions about cancer treatments including surgery for lumpectomy, mastectomy, or preventive mastectomy. Then at the same time, asked whether or not they want to undergo breast reconstruction to restore one or both breasts, and expected to choose which type of reconstruction to have. This is a lot to consider.

In this booklet, we shed light upon this very personal decision, specifically to clarify information about:

- Breast reconstruction and non-surgical options available for women affected by breast cancer
- Short and long-term expectations
- Common medical and emotional influences
- Important questions for women to ask themselves and their medical team

Our goal is to provide education, resources, and support that will help anyone exploring breast reconstruction make more comfortable and confident decisions within a time frame that feels reasonable.

This booklet has been created, with care, based on survey results from a 2010 survey of 840 women in the U.S. with breast cancer; a focus group of nine breast cancer survivors who shared their experiences; with insight from our partners: Bright Pink, FORCE, Living Beyond Breast Cancer, and Young Survival Coalition; and with professional guidance from medical, oncology, plastic surgery, and psycho-oncology experts. Thank you to all contributors.

There are many influences that impact women's decisions. CSC's 2010 survey of 840 women with breast cancer found that 70% of the women chose reconstruction after mastectomy to improve their body image and 73% wanted to improve their physical appearance. Of the women who opted not to undergo reconstruction, 62% were concerned about side effects, 59% didn't want additional surgery, and 42% were worried about cancer recurrence.

1

The Impact of Cancer

Being handed a cancer diagnosis is devastating, with unknowns that may affect many aspects of life.

Yet, after the immediate crisis of a diagnosis is over, most women learn coping skills that enable them to manage the difficulties of breast cancer without long-term physical, sexual or emotional problems.

Learning to ask questions about your options can empower you to navigate your decisions and cope more effectively with your cancer experience, treatment, and other life changes after cancer.

It's not uncommon to have concerns about your overall health, self-image, and the future. While difficulties with daily activities, career, finances, and relationships can happen as a result of cancer, they can also be overcome with good coping skills, accurate information and an accessible network of support.

EMPOWER YOURSELF

You are the expert in your cancer experience in relation to how you feel, what is important to you, and what you want.

“Empower Yourself” is a phrase that describes the ongoing process of becoming educated about your cancer diagnosis, your treatment and reconstruction options, your medical team, and ways to improve your physical, mental and spiritual wellbeing after cancer. Becoming “empowered” is about regaining a sense of control and confidence after receiving a cancer diagnosis.

If you have the confidence to ask important questions of your healthcare team, you will, often, be able to make decisions about cancer treatment and recovery that work for you.

If you start to feel overwhelmed, try to take a step back and give yourself the time you need to make a comfortable decision about breast reconstruction or any other decisions related to your treatment.

10 ACTIONS YOU CAN TAKE TO FEEL EMPOWERED AFTER BREAST CANCER

- 1. Remember this is YOUR body and YOUR decision.** Decisions about breast cancer treatment and reconstruction are very personal and they are yours to make. How do you feel about your breasts as part of your self-image? How will breast surgery affect your life? Develop a plan with your oncologist, surgeon, partner, friend, family. Determine what you feel most comfortable with.
- 2. Take one step at a time.** Take a moment to slow down when you feel stressed or overwhelmed. Allow yourself to think carefully about what you need to do. You have time to gather information and make an informed decision.
- 3. Seek support from others.** People often find comfort and answers when talking with others who share common experiences and challenges. Contact the organizations listed as resources throughout this booklet to find a support group or connect with others.

- 4. Communicate openly with your healthcare team.** Having an open and honest relationship with your medical team will help to increase trust and help you feel a greater sense of control. Even when your medical team includes people you've only just met, talk with them about your concerns and questions. Consider a second opinion, especially when discussing reconstructive surgery.
- 5. Prepare a list of questions for each appointment.** Ask for clarification of terms you don't understand. Ask about your options—about breast reconstruction now vs. in the future or not at all. Ask about recovery time, after-effects, treatment considerations, long and short-term expectations. It is valuable to bring someone with you to take notes and help you consider what was said.
- 6. Express your feelings.** Cancer and the treatment process are stressful and they tend to trigger many strong emotions. It helps to find ways to acknowledge the range of feelings you have: journaling, blogging, support groups, or professional counseling are just a few useful strategies.
- 7. Openly ask for support.** Friends and family often want to help, but don't know how. They will appreciate specific examples of support, such as preparing meals, making phone calls for you, joining you for a movie – or – take someone with you to medical appointments to take notes and discuss what you heard afterwards.
- 8. Learn to relax.** Learning to find a calm, controlled physical state can reduce your stress. Treat yourself kindly. Consider a relaxation program or engage in calming activities, such as walking, yoga, reading, meditation and music.
- 9. Strive for a “new normal.”** A breast cancer diagnosis can be life changing. It can be an opportunity to reprioritize goals and reframe your self-image. Focus on living in the present and enjoying every moment with the people you care about – with appreciation for your body.
- 10. Maintain a spirit of hope. You may have cancer, but cancer does not have you!** Remember that many women have survived a diagnosis of breast cancer. Draw upon your spiritual beliefs, cultural customs, friends and family connections. Hope can be a motivating factor in your recovery.

2 *Making Your Decision*

NAVIGATING DECISIONS

When one or both breasts are completely removed during mastectomy to remove cancer (for example), a woman will be faced with the option not to have additional surgery and leave her chest as is, or to undergo reconstruction to restore her breasts.

When you are diagnosed with cancer and are told about striking surgical options such as these, you will likely experience a wide range of emotions. It's difficult to know where to begin and you may feel lost or even unable to make decisions.



First you must decide whether or not you want reconstruction and if it's important to you. Then research your options. Find out what's possible...but first it's imperative to decide if you want it. It's very individual and very personal.

— Sandy

CHECK-LIST: THINGS TO CONSIDER FOR BREAST RECONSTRUCTION

- ✓ **Your feelings and emotions** – How will the loss of a breast affect the way you view your body or sexual identity (body image)? The relationship a woman has to her body is highly personal and feelings about physical changes will vary from woman to woman.
- ✓ **Your health** – Will your cancer diagnosis, other medical conditions that affect healing, and/or your treatment history (including experience with radiation or chemotherapy) impact your options for reconstruction?
- ✓ **The need for multiple appointments or surgeries** – Does it matter that the reconstruction process involves multiple steps? Reconstruction can involve multiple visits for tissue expanders, adjustments after the initial surgery, nipple reconstruction, long-term reconstruction repair, or other corrective surgery.
- ✓ **Potential scarring** – Will scars beyond the breast bother you? For some reconstruction procedures, scars may be obvious on parts of the body where tissue was removed as well as on the reconstructed breast. You may choose additional plastic surgery to minimize scars.
- ✓ **Absence of feeling** – Do you care that reconstruction restores the shape of the breast but not sensation (although sensitivity may improve in time depending on the procedure)? No matter what, sensation is greatly or completely diminished with the removal of a breast.
- ✓ **Appearance** – If you have a single mastectomy, would you want to reshape the uninvolved breast to match the appearance of the reconstructed breast (with a reduction, a lift, or an enlargement)? Some women do not want to have additional surgery because of scarring, prolonged recovery time, and the loss of sensation. If you have a double mastectomy, would you consider a uniform new size for both breasts?
- ✓ **Texture** – Will the texture and consistency of a reconstructed breast feel like breast tissue? It's extremely helpful to talk with women who have had each type of breast reconstruction you consider to ask how they experience the texture of their reconstructed breasts among other questions.
- ✓ **Recovery** – How will your lifestyle be affected during the recovery time? For example, recovery from a mastectomy alone is relatively faster than a mastectomy plus reconstruction. Ask about the short and long-term impacts from each type of reconstruction procedure that you can consider.
- ✓ **Future repair** – How long will reconstruction outcomes last? Many procedures don't last forever. For younger women, it is important to ask if there might be a need for reconstruction surgery in the future to correct for physical changes.

It is important to acknowledge your fears and feelings, as painful as they may be. This is a crucial step towards becoming informed, supported, and ultimately empowered. Operating from a place of clarity will enable you to make informed, timely decisions throughout your cancer experience.

Take a moment to prioritize what's important to you when considering your breasts after cancer. How you felt about your breasts before cancer, your treatment plan, and other considerations will influence how you wish to deal with reconstructive surgery.

On average, one out of every three women affected by breast cancer chooses to have breast reconstruction immediately after a mastectomy or lumpectomy. Those who don't choose to have reconstruction immediately may revisit the idea in the future.

The other two out of three women who do not choose immediate reconstruction, may make this decision for the following reasons:

- they don't have this option (late stage cancer, other health reasons, etc.)
- their breast doesn't change much after a lumpectomy
- they don't know about their reconstruction options or insurance benefits
- they would prefer to consider reconstruction after having more time to recover from cancer
- or they ultimately determine that reconstruction is not the right choice for them

More information about timing considerations for reconstruction is in Chapter 4. Also, when making the decision to undergo reconstruction or not, you should weigh the pros and cons of each procedure (see chart in Chapter 8), including personal factors that may involve family responsibilities, workplace concerns, or expectations.

START WITH A TREATMENT PLAN

Decisions about breast cancer treatment requires you and your doctor to discuss many different concerns, but the single most important factor for initial treatment is the stage of your breast cancer.

Tumor stage determines whether surgery, radiation therapy, hormone therapy, chemotherapy or some combination of those therapies is the best option for your treatment success.

Earlier stage breast cancers typically include surgery as part of the treatment plan. Depending on the stage of the tumor, the size of the tumor, and the involvement of surrounding lymph nodes and tissue, either breast-conserving surgery (lumpectomy), or mastectomy may be proposed.



I think it's important to speak with someone who's been through it. I felt lost and had nobody to talk to — I felt pressured. I now know it helps so much to find sources of information and people you feel comfortable with.

— Francis

TYPES OF PRIMARY BREAST SURGERIES

Breast-Conserving Surgeries

- **Lumpectomy** – the tumor ('lump') and a small amount of surrounding normal tissue is removed.
- **Partial mastectomy or segmental mastectomy** – the part of the breast that has cancer and some surrounding normal tissue is removed.
- **Axillary lymph node dissection or sentinel lymph node biopsy** – some of the lymph nodes under the arm may be removed for evaluation.

Mastectomy

- **Total or simple mastectomy** – the breast with cancer is entirely removed. Some lymph nodes may also be removed for evaluation (lymph node dissection).
- **Modified radical mastectomy** – the breast with cancer is entirely removed, along with lymph nodes and the lining over the chest muscles.
- **Radical mastectomy/Halsted radical mastectomy** – the breast with cancer is entirely removed, along with all lymph nodes and the chest wall muscles under the breast.

- **Skin sparing mastectomy** – preserves as much skin as possible, removing only affected breast tissue, nipple, and areola, leaving skin for reconstruction.
- **Nipple-sparing mastectomy** – removes breast tissue while leaving skin, nipple and areola for reconstruction.

In some cases with women who have small breasts, a lumpectomy can remove enough breast tissue that it can have the same impact as a mastectomy in terms of breast loss, though a surgeon will do as much as possible to conserve the breast.

Radiation therapy is usually recommended after a lumpectomy and may additionally alter the breast, making it firmer and/or smaller in appearance.



Radiation did things to my breast tissue that I didn't expect — the sensations are different, the size is different, and the radiated breast doesn't really function the way the other one does, but I've been fine with it for the past 24 years.

— Susie

Women may choose a **unilateral prophylactic mastectomy** (versus a **bilateral prophylactic mastectomy** which involves both breasts removed by choice) even if the stage of their cancer indicates that lumpectomy is an option. Some women will choose to have a **contralateral prophylactic mastectomy** (the removal of unaffected breast tissue, by choice, due to high genetic risk). These are individual decisions that should be made after careful consideration with guidance and support from your doctors and family.

If you have a family history of breast or ovarian cancer, your doctor may recommend a genetic test and discussions with a genetic counselor, among your other doctors, before making a decision about surgery or reconstruction. See p. 12 for more information.

CONSIDER THESE QUESTIONS: LUMPECTOMY VS. MASTECTOMY

1) How do your breasts affect your self-image or sexual identity?

For some, the loss of a breast may not matter when health concerns take center stage – and they can adapt to a post-surgical body over time with a prosthetic breast. For others, breasts are an intrinsic part of their self-image and sexual identity. For those women, a mastectomy with reconstruction is one option, or a breast-conserving lumpectomy with or without reconstruction is another.

2) Are you prepared to have radiation treatments if you opt for a lumpectomy?

You may need to set aside six or more weeks for breast radiation after a lumpectomy. This can involve daily appointments. If you've had prior radiation treatments, learn whether or not your body can have more radiation, and ask about permanent changes that radiation may cause.

3) Will you be comfortable with monitoring your breast if you opt for a lumpectomy?

If you are comfortable with follow-up cancer monitoring, such as check-ups every 6 months to 1 year, and an MRI every three years, you may opt for a lumpectomy rather than a mastectomy.

4) Do you have a family history of breast cancer?

If you have a high risk for cancer or cancer recurrence due to genetic risk, you may be a candidate for a prophylactic mastectomy. Ask your doctor to refer you to a genetics expert to learn about testing for the main hereditary breast and ovarian cancer (HBOC) syndromes caused by gene mutations in BRCA1 or BRCA2. These mutations can substantially increase a woman's risk for breast and ovarian cancer. Genetic counseling and testing can help determine your cancer risk, and a breast surgeon can help explain your surgical options.

5) What cosmetic results will you be content with after breast cancer surgery?

For some women, a lumpectomy is minimally invasive leaving only a dimple in the breast when healed. For others, a lumpectomy may cause a noticeable change in the breast shape. With a unilateral mastectomy (one breast is removed), you may wish to balance your appearance with reconstruction or a prosthesis. With a bilateral mastectomy (both breasts are removed), you may wish to create smaller or larger breasts than your original size. Talk to your surgeon about what might give you the best cosmetic result.

WHEN TO CONSIDER PROPHYLACTIC MASTECTOMY

If you have a family history of breast or ovarian cancer or if you have a gene mutation in one of the genes called BRCA1 or BRCA2, your lifetime risk for breast cancer is very high. If you have a BRCA1 or BRCA2 mutation and have already been diagnosed with breast cancer, you may be at increased risk for a new diagnosis. Some women with these mutations choose preventive (prophylactic) mastectomy of one or both breasts, even if the breast tissue is currently non-cancerous.

Prophylactic mastectomy and prophylactic oophorectomy (surgery to remove ovaries for cancer prevention) have been shown to significantly reduce cancer risk for genetically prone individuals. It is important for women considering these procedures to discuss with their doctor how these surgeries can impact other decisions, such as reconstruction.

Genetic counseling and testing can help with treatment and reconstruction decisions. For example, say “Pam” has breast cancer in her left breast and undergoes a unilateral (one sided)

mastectomy with reconstruction using a DIEP flap (abdominal tissue). If later, Pam undergoes genetic testing and learns she has an abnormal BRCA gene, she may be advised to undergo a prophylactic mastectomy on the right side. Because she has already used her abdominal tissues for the first reconstruction, she will have to choose a different type of reconstruction for the right breast. If genetic counseling and testing were done prior to the original mastectomy and reconstruction, she might have chosen to have both mastectomies done together and been able to have reconstruction on both breasts simultaneously.

It is important to note that genetic testing and prophylactic mastectomy is not necessary for all high risk patients. Each patient should speak with her breast surgeon and/or oncologist about family history, personal risk, and treatment options. For more information, visit the **National Society of Genetic Counselors** www.nsgc.org, **Bright Pink** www.BeBrightPink.org, and/or **Facing Our Risk of Cancer Empowered** www.facingourrisk.org.

TIMING CONSIDERATIONS

Based on your health, breast surgeons either suggest immediate reconstruction, or delayed reconstruction after you've healed from cancer surgery. You should know that you may still have the option to undergo reconstruction or alternate reconstruction procedures, even many years later.

For women who choose mastectomy, breast reconstruction can be an option:

- At the time of mastectomy (**immediate breast reconstruction**), or
- At a later date of your choosing (**delayed breast reconstruction**)

The advantages of **immediate reconstruction** include potentially more chest tissue to support reconstruction because there is no surgical scarring or damage from radiation therapy (unless you had that earlier in your life). And, although multiple surgeries may be required for reconstruction, scheduling the initial step at the same time as the mastectomy means less surgery and exposure to general anesthesia, and the ability to recover from everything at the same time. Another advantage is that your physical changes after a mastectomy are not as dramatic.

Delayed reconstruction can allow you more time to adapt emotionally and to research your reconstruction options. Some women prefer to have more time to recover from their mastectomy before beginning reconstructive surgery. In other cases, women who smoke, are overweight, or have diabetes will be asked to wait to avoid surgical risks.

If radiation therapy is or was part of your treatment plan, you should ask about the best timing for reconstruction to reduce damage to the reconstructed breast (radiation reduces the elasticity of skin tissue and can impact reconstruction.) Or, if you smoke, most surgeons will require that you stop before reconstructive surgery.

Most women will not be able to predict how they'll adapt to body image changes after a mastectomy until they experience those changes. It is reassuring to know that you can still choose to alter your breasts at a later date. It is also helpful to know that many women who choose not to undergo reconstruction learn to be content with that decision too. (More information about living without reconstruction is in Chapter 3.)

We discuss reconstruction options in more detail in Chapter 4 and the chart in Chapter 8.

YOUR CHANGING BODY IMAGE

Reconstructed breasts do not have the same feeling and sensation as natural breasts. On the other hand, they can look very much like your natural breasts – and look great with clothing. In some cases, women like their breast size and shape better after reconstruction. It is important to realize, however, that no surgery will make your breasts look, feel, or have the same sensations as before surgery, nor can it erase the distress caused by cancer.

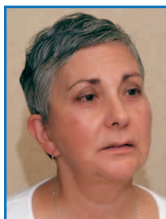
Reconstruction can be a tool to help you feel whole again, and help you get back on track. Many women find, however, that moving on has much more to do with personal courage and perseverance.

Knowing this, it is still helpful to get a better idea of how you might look after reconstruction. It is a good idea to ask your plastic surgeon to show you pictures

of the results of the different types of reconstruction that you are considering – or show you how mastectomy scars look without reconstruction.

Ask your plastic surgeon to connect you with at least one former patient who has had the same surgical procedure that you are considering. Most plastic surgeons will have picture books for you to look at, as well as former patients who would be willing to talk with you about reconstruction.

Because this is a big decision and some reconstructive surgeons prefer or specialize in certain procedures, you should not hesitate to seek a second or even third opinion with other plastic surgeons to ensure that you have heard all of the available options tailored for you.



Take your time if you can. The more time you have to talk to people, learn what you can, etc. the more likely, I think, you'll have a positive outcome.

— Norma

ONLINE SOURCES FOR BREAST RECONSTRUCTION PHOTO GALLERIES

Some great websites and bulletin boards that share “After Reconstruction” images and real testimonials include:

- **The American Society of Plastic Surgeons.** www.plasticsurgery.org – offers before/after photo gallery of breast reconstruction.
- **www.breastcancer.org** – illustrates different breast reconstruction surgery types with a photo-gallery of women, and their stories about their reconstruction experience (search “photos”).
- **Facing Our Risk of Cancer Empowered.** www.facingourrisk.org/photogallery – has a password-protected photo gallery of real women who share their experience and a discussion board open to anyone.
- **Your Breast Options.** www.yourbreastoptions.com – offers comprehensive information about breast health, breast cancer awareness and breast reconstruction options, including testimonials (no images).
- **Young Survival Coalition.** www.youngsurvival.org – has ongoing dialogues by women about reconstruction, among other issues, in their open bulletin board. YSC also offers an important list of Questions and Answers about breast reconstruction on their site as well as access to the SurvivorLink program.

Always ask your plastic surgeon to show you before/after images of their results with the reconstruction procedures you are considering.

OTHER PRACTICAL CONSIDERATIONS

Choosing Your Medical Team

In general, there are five or six key individuals who can help you make appropriate decisions regarding your entire treatment experience.

1. **Your primary care physician**, who understands your history, preferences, and how you would like to manage your general health throughout your treatment and beyond. Plus, your primary care physician can coordinate the team that will help you manage treatment decisions along the way.
2. **Your breast or general surgeon** would make the initial surgical recommendations, determines if you can have a breast-conserving operation or a mastectomy, refers you to an oncologist, radiation oncologist, and/or plastic surgeon, and helps review what options you may have for reconstruction, if appropriate.
3. **Your medical oncologist** specializes in the treatment of cancer, and will offer cancer treatments and referrals with respect to chemotherapy, hormone therapy, radiation treatments or any other therapy after surgery.
4. **Your radiation oncologist**, if you need radiation, can discuss the timing of radiation therapy in conjunction with breast reconstruction, which is a very common part of many women's cancer treatment.
5. **Your board certified plastic surgeon**, if you are considering reconstruction, can discuss the many reconstruction techniques available and what might be best for you and your situation. Ask about long and short term expectations.
6. **Your support team**, including a nurse navigator, can help you work through decisions and your emotions; often offering a great sense of strength and support. This can include a support group or one-on-one counseling with an oncology social worker or psychologist.

You should find people you can trust and with whom you can communicate openly. If you feel intimidated or rushed by anyone, seek a referral to someone else.

To find referrals for a qualified, board certified plastic surgeon, you can search the **American Society of Plastic Surgeons** website: www.plasticsurgery.org

If you are interested in reconstruction, you'll want to make sure that you learn about all types of breast reconstruction options and which would be acceptable for you. See Chapter 4.

Consulting with a reconstructive plastic surgeon (certified by the American Board of Plastic Surgery) before you make a decision about surgery will provide you with valuable information. Plastic surgeons specialize in different aspects of breast reconstruction, so ask questions!



I wish I had more information about how reconstruction would feel afterwards. If I could do it again, I would ask my surgeon more questions.

— *Judy*

CSC's 2010 survey suggests that 86.8% of women who discussed breast reconstruction options with a plastic surgeon at the time of diagnosis (as opposed to a later date) were mostly or extremely satisfied with their decision to undergo reconstruction.

When my patients see me for the first time for breast reconstruction, they are often just beginning to gather information. This booklet will provide them with key points to make their visits with me significantly more fruitful. There is a great deal to learn and digest, and nobody can absorb it all in one office visit. Having this book as a reference will make the entire process less confusing. By giving patients the information they need to make an informed decision in regards to their bodies, they will feel more confident about the decisions they make.

— *Dr. Leif Rogers, F.A.C.S., Beverly Hills, CA*

BACK POCKET QUESTIONS

As you search for answers about breast reconstruction, bring a written list of questions. Here are some examples:

GENERAL QUESTIONS FOR THE SURGEONS TREATING YOUR CANCER

- Am I a candidate for lumpectomy or would you recommend a mastectomy and why?
- What is the risk of cancer developing in my other breast?
- What monitoring would you recommend for my other breast?
- Am I a candidate for reconstructive surgery?
 - What's the difference, for me, with respect to getting reconstruction now (as my cancer is being treated/during initial surgery) vs. in the future?
 - How will my other treatments (i.e. chemotherapy or radiation or follow-up care) affect reconstruction or vice versa?
 - What will my insurance cover and what will be my out-of-pocket expenses?
- What happens if cancer returns beneath a reconstructed breast?
- How long will I need to stay in the hospital for each type of surgery?
- Can I talk with someone who has had the type of reconstruction I should consider? And with someone who's chosen not to undergo reconstruction?
- What sort of follow-up will I require if I choose lumpectomy over mastectomy?
- How long would it take for me to resume normal activities (employment, child care, driving, sex, exercise...) after surgery?
- Can you offer me a few referrals to plastic surgeons?

Notes / Additional Questions

QUESTIONS ABOUT RECONSTRUCTION FOR A PLASTIC SURGEON

- What are the types of reconstruction surgery available to me?
- Which would you recommend and why? (different surgeons may give you different answers – it can help to get a second or third opinion)
- Will my breasts look relatively the same? Will they be symmetrical?
- Would you recommend surgery for the opposite breast for symmetry (lift, reduction, augmentation)?
- Will I regain sensation?
- What will reconstructed breast(s) feel like? (How will they feel on my chest?)
- What will my scars look like?
- How much experience do you have with this type of reconstruction?
- What side effects or possible complications should I know about?
- How many surgeries will I need?
- What type of pain or discomfort should I expect, and for how long?
- How long is the reconstruction process from start to finish?
- How long is the recovery period for my type of reconstruction?
- How will the reconstructed breast respond to aging and/or weight gain/loss? How do they change over time?
- Do you have pictures of results from previous surgeries you've done that I could look at?
- Can you put me in touch with a past patient of yours who's had this type of reconstruction?
- What happens if my cancer returns after I've had reconstructive surgery?
- What sort of follow-up is necessary for my reconstructive choice?
- How might pregnancy affect my choice?
- Will I be able to breast feed?
- How will chemotherapy and/or radiation therapy affect my reconstruction?
- How long should I expect the outcome of my reconstruction to last? (Will I ever need replacement surgery?)

3

Choosing not to Undergo Reconstruction



You need to talk to people you can identify with because everybody is different. For me, I never had cleavage and my breasts weren't a huge part of who I am. For other people, breasts really matter.

— Bette

PERSONAL CHOICE

It is important to remember that breast reconstruction is not for everyone. Every woman is different, and there is no wrong decision.

For some women, reconstruction may not ever be an option for a variety of factors including, but not limited to, their diagnosis or health status. For example, if cancer is advanced, reconstruction may not be recommended; or if a woman is very thin she may not be a candidate for certain procedures.

When presented with the choice, some women elect not to undergo reconstruction for their own personal reasons. These women may be focused on getting back to work and family routines with minimal disruption to their schedules and without prolonged recovery times from additional surgery. A woman may find it easier to live an athletic lifestyle without breasts; while others just want to “get the cancer out” and move on with their lives.

In the “Personal Considerations” (Chapter 6) of this booklet we discuss issues of loss that most all women feel after breast surgery, as well as issues of body image and sexuality, which are critical to consider as a woman moves beyond cancer and finds her “new normal.”



TREE poster, Deena Metzger

*Women can feel beautiful with
or without reconstruction surgery.
Beauty comes from within.*

BREAST FORMS AND PROSTHESES

An alternative to reconstruction is a breast form designed to simulate the appearance of a natural breast under clothes. A breast form, or prosthesis, is worn inside the bra or attached to the body with adhesive strips (attachable or contact prosthesis). It should be professionally fitted once your doctor determines that your mastectomy site has adequately healed.

Breast prostheses come in a wide range of shapes, sizes, and skin tones. The costs are generally covered by insurance. Prostheses also come in different materials.

A silicone prosthesis most naturally imitates the weight and drape of the breast. A silicone breast form is weighted so that your posture is restored and you feel balanced when you move and walk. It creates a natural appearance in clothing and allows your clothes to fit the way they did before your mastectomy.

Non-silicone breast forms (foam rubber, fiberfill, or cotton) are also available and are lighter, cooler and less expensive. You may choose to wear the bra you have always worn or a special mastectomy bra with a pocket for the breast form. You may also have your own bras modified to fit the breast form.

Soft bras are available for nighttime use if you prefer to wear your prosthesis under your nightgown.

After surgery you will be given a temporary prosthesis to wear during your recovery. When ready, you can be professionally fitted for a prosthesis that will fit into pockets sewn into your bra (and swimsuits).

Always have your physician write a prescription for your breast prosthesis and mastectomy bras. Determine what costs your insurance company will pay and keep good records of your expenses.



I opted to have my second breast taken off right away. I kind of miss that having one natural breast helps keep the prosthesis in place - but special bras help.
— Nancy

Some resources with information about breast prostheses:

www.tlcdirect.org, American Cancer Society's "TLC Catalog"

www.amoena.com, Amoena Breast Forms

www.breastprosthesis.net, listing several prosthesis manufacturers and retailers

www.anita.com, Anita care comfort products

4 *Choosing Breast Reconstruction*

Breast reconstruction is a surgery performed after mastectomy to rebuild the breast, restoring its shape and size. The nipple and the areola (dark area around the nipple) can also be reconstructed or even spared. It is important to choose a plastic surgeon who is experienced in breast reconstruction specifically.

If you haven't yet had your mastectomy, it is important to discuss reconstruction options with at least one breast or plastic surgeon prior to your mastectomy, to explore the opportunity to begin reconstruction at the same time your mastectomy is performed.



I'm very happy with my decision to undergo breast reconstruction. This may not be the path for everyone, but it was the right thing for me and I don't think there should be a stigma around any decision you make.

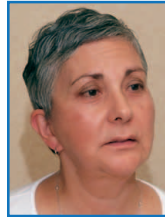
— Sharishta

If you have a medical oncologist, it is also important to have your plastic surgeon talk with him/her about the cancer treatments you've had. For example, immediate reconstruction may not be an option for someone who is required to undergo radiation therapy.

There are four general surgical approaches to restore the shape of the breast:

- Use of an implant (saline or silicone)
- Use of tissue from another part of your body (abdomen, back, thighs, etc.)
- Use of an implant and tissue from your own body (combination)
- Rearrangement of your own breast tissue after a lumpectomy

On pages 42 - 53 you will find a chart that compares the different breast reconstruction methods and shares some of the pros/cons about each one.



With breast cancer two very visible signs of being female can be removed: your hair with chemo and your boobs with mastectomy. Reconstruction gives you a chance to feel more like you did before - but there are things I wish I knew before jumping in.

— Norma

IMPLANT RECONSTRUCTION

There are two common types of implants available for reconstruction: a saline implant, which is a silicone form filled with sterile saline (similar to salt water), and a silicone-gel filled implant. Ask your surgeon if you can feel a sample of both types; and try to talk with women who've had each type.

Implant procedures can be divided into two types:

- **Direct to Implant** – surgery with an implant is performed in one stage, at the same time as your mastectomy. After the surgeon removes the breast, an implant is placed under the chest wall muscle. Keep in mind, additional surgery may be needed for a revision or for nipple reconstruction.
- **Expander Implant** – done in two stages, the use of a tissue expander allows the body to create space and enough skin for an implant after a mastectomy. A tissue expander, similar to a balloon, is placed under the skin and muscle where the breast was removed. Saline is inserted into the expander at the time of the mastectomy and gradually over the next few weeks to up to 6 months, through a small valve in the implant. Women comment that expanders feel tight or “like rocks” while in place. When the breast area has stretched adequately, a second surgery is performed to remove the expander and replace it with a permanent implant.

CONCERNS ABOUT IMPLANTS

Fears about silicone leakage has led the U.S. Food and Drug Administration (FDA) to evaluate breast implants. The FDA has determined that most silicone filled implants are safe for both reconstruction and cosmetic reasons. Some silicone implants are still being evaluated in FDA approved clinical studies, you can check with your surgeon for details.

Discuss any concerns you have about implants with your surgeon. You should know that implants may need to be replaced with surgery at some point in your lifetime. Implants can leak or tear, cause an infection, or develop scar tissue – but these things can be managed effectively with your surgeon.

More on breast implant safety is available at:

FDA (Food and Drug Administration) website:

www.fda.gov/MedicalDevices/ProductsandMedicalProcedures/ImplantsandProsthetics/BreastImplants/ucm063717.htm

National Cancer Institute

Breast Implant Study Fact Sheet:

www.cancer.gov/newscenter/siliconefactsheet

RECONSTRUCTION WITH A TISSUE FLAP

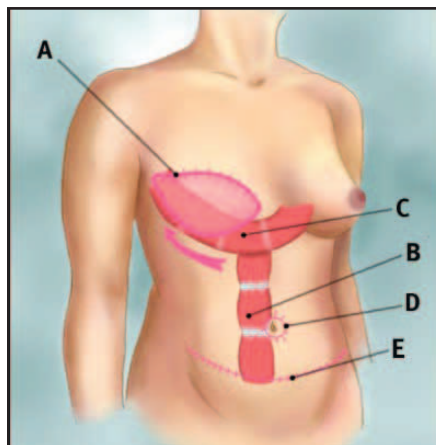
A tissue flap procedure uses tissue from your body — your abdomen, back, thighs or buttocks — to rebuild the breast. When your own tissue is used to create a new breast, the general term for the procedure is called **autologous reconstruction**.

Tissue flaps behave more like your own body than implants — for example, they shrink or expand when you lose or gain weight. Tissue flap procedures result in two scars — one at the breast and another at the site where tissue was removed. It is possible that the tissue removed from your abdomen for a reconstructed breast can cause changes, for example, in the shape of your belly button. In some cases, the abdomen may require support as it heals after a tissue flap procedure to minimize problems such as hernias or bulges. These are things you may want to ask more about.

There are several types of tissue flap procedures:

- **TRAM (transverse rectus abdominis muscle) Flap** - tissue from the abdomen (including skin, fat, blood vessels and at least one abdominal muscle) are used to rebuild the breast. In addition, an implant may be used to create a fuller shape. There are two types of TRAM flaps:

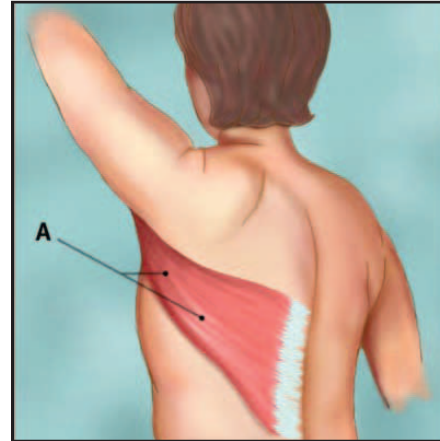
- a **pedicle flap** where the tissue remains attached to its original blood supply and is tunneled under the skin to the breast area
- a **free flap**, where the tissue is cut away completely from its original location and is attached to a new blood supply in the chest area. Free flap procedures use microsurgery techniques to connect blood vessels and ensure adequate circulation to the site.



Woman in process of TRAM flap reconstruction

- A) lines of reconstructed breast incisions
- B) right trans rectus abdominis muscle
- C) left TRAM muscle is swung over to re-create the new breast
- D) incision circle of re-positioned “belly button” incision
- E) line of abdominal surgery

- **Latissimus Dorsi Flap** – a pedicle flap procedure where tissue and muscle from the upper back is tunneled under the skin to the breast area, creating a pocket for an implant.
- **DIEP (deep inferior epigastric artery perforator) Flap** – a free flap procedure using fat and skin, but not muscle, from the lower abdominal area. A **SIEA (superficial inferior epigastric artery) Flap** uses skin and fat from the lower abdominal. The relocated tissue is attached to a new blood supply in the chest.
- **Gluteal free flaps** – free flap procedures where tissue from the buttocks, including muscle, is relocated to the breast area and connected to a new blood supply there in order to recreate the shape of the breast. **IGAP (inferior gluteal artery perforator) Flap**, and **SGAP (superior gluteal artery perforator) Flap** are also done. If necessary, an implant can also be used to fill out the size of the new breast.
- **TUG (Transverse Upper Gracilis) Flap** – a free flap which builds a breast from a small muscle plus skin and fat from the upper inner thigh. It can be performed on one or both breasts at the same time or separately.



Latissimus dorsi muscle is swung forward to re-create the new breast.

A) latissimus dorsi muscle

To help tissue grow and heal, surgeons use synthetic mesh and more recently, **acellular dermis (ADM)**, which is donated human skin with the cellular elements removed, leaving behind a collagen matrix to support the tissue expander or single stage reconstruction process. ADM may be used to help support the chest wall musculature and the breast implant under the mastectomy flaps.

More information about ADM can be found at www.lifecell.com or www.mtf.org.

TISSUE REARRANGEMENT

Oncoplastic surgery is the rearrangement of tissue in the affected breast and a symmetry procedure on the unaffected breast. Oncoplastic surgery is appropriate for women with large breasts who desire a decrease in size. Once the general surgeon has performed the lumpectomy and feels comfortable that the cancer is surgically removed, a plastic surgeon can rearrange tissue to correct the defect remaining from the lumpectomy and at the same time perform a reduction (mastopexy) on the other side. Radiation can be performed after reconstruction.

CELL ENHANCED LUMPECTOMY REPAIR

Although lumpectomy and partial mastectomy are breast-conserving surgeries, a scar is created and a dimple or indent is left behind. A new option — **cell enhanced breast reconstruction** — is being explored in clinical trials to help correct these problems. Fat tissue, which is rich in stem cells, is adapted in a special process that enables it to be used at the lumpectomy site.

Also, fat grafting is a technique that may improve tissue damage after radiation, and may improve breast reconstruction outcomes after radiation treatment.

NIPPLE AND AREOLA RECONSTRUCTION

Nipple and areola reconstruction is a separate surgery and is usually the final step in breast reconstruction. Tissue from the reconstructed breast, opposite nipple, abdomen, eyelid, groin, inner thigh or buttocks can be used to recreate a nipple. Because reconstructed nipples tend to shrink, they are initially made up to 50% larger than the desired size. Tattooing can give the nipple a natural color and create an areola.

For some women, a **nipple-sparing mastectomy** is an option. This type of surgery is performed when cancer is at an early stage located far from the nipple, or during a prophylactic mastectomy.

In Chapter 8, p. 52, you will find a chart that compares different nipple and areola reconstruction methods and shares some of the pros/cons about each. Newer methods, such as three-dimensional tattooing, may be also available with local experts.

CONCERNS ABOUT SURGICAL COMPLICATIONS

Like any major surgery, your surgeon should explain and discuss the complications and time commitments associated with your specific procedure, as well as methods to prevent problems. Ask questions so that you fully understand risks before making your decision. (See the chart on pages 42- 53 for a summary of some of the risks for each surgery.)

Surgery, in general, can pose a number of risks (infection, bleeding, blood clots, pain, reactions to medications or general anesthesia, etc.). However, each individual is unique and reacts differently – ideally problems can be avoided or well managed.

Stay on top of changes that you experience and stay in touch with your doctor if you are concerned about something that doesn't look or feel right.

These things can happen and can be corrected with the help of your surgeon.

- Swelling, redness, or infection
- Painful scars or excess scar tissue distorting the new breast
- Stitching that opens before healing
- Problems with drains (i.e.: pooling blood and fluid at the mastectomy site)
- Necrosis (i.e.: circulation problems causing the skin around the implant to die)
- Saline leakage
- Cosmetic problems

5 *Planning for Reconstruction and Recovery*

PLANNING FOR SURGERY

Prior to surgery, your health status will be assessed. Tell your doctor or nurse about all medications that you take, including prescription drugs, over-the-counter medicines, and vitamins and herbal supplements.

You will be asked to stop taking blood thinners, aspirin products, anti-inflammatory medications such as ibuprofen, vitamin E and all herbal drugs. Some doctors will ask you to begin taking a stool softener a few days prior to surgery because pain medication can cause constipation.

Exercise, get plenty of rest, and eat well so that you will be as healthy as possible prior to surgery. If you smoke, you should stop. Some surgeons will not perform breast reconstruction procedures on smokers because surgical wounds may not heal as well; this can also delay other forms of treatment you may need.

Your recovery period can be more comfortable if you anticipate your needs before you return home. Planning meals in advance or lining up assistance from family or friends, for example, is helpful.

You will not be able to lift heavy items (a rule of thumb is nothing heavier than an old phonebook) so gallon jugs of milk or large bags of pet food should be put in smaller containers. In most cases, you will not be able to raise your arms above your head right away – soft, oversize or front button-down shirts will be most comfortable. This discomfort will disappear over time with exercise. Physical therapy may be especially helpful for women who have had radiation or a flap procedure.



Exercise really helps. I originally felt very uncomfortable after my reconstruction — I lost arm movement after my latissimus dorsi surgery. Physical therapy, swimming and yoga helped me feel so much better and regain movement.

— Liz

CLOTHING & COMFORT TIPS

(Immediately following reconstructive surgery)

- Button-down shirts and pajamas are much easier to take on and off when it's difficult to raise your arms.
- Camisole tops with a shelf-bra are easy.
- If you are having a procedure like the TRAM flap, you will want to wear loose pants.
- Slip-on shoes or slippers/flip flops, preferably with a rubber sole, will be more comfortable when it's difficult to bend.
- Set-up your bed with lots of pillows for support and positioning, including a large pillow with armrests or long body pillow.
- If you undergo radiation therapy or a flap procedure, a physical therapist can help expedite healing and build strength for comfort.
- A small, inexpensive step stool will help to reach high shelves and cabinets.
- Anti-stretch creams like shea or cocoa butter can help with dry skin.
- Ask about other ideas for comfort.

WHAT TO EXPECT FOR SURGERY

Reconstruction surgery is performed in a hospital, at an ambulatory surgery center, or at an office-based surgical center. Depending on the type of breast reconstruction procedure you choose, you will either go home the same day or remain in the hospital for a few days. Some follow-up procedures may be performed in your plastic surgeon's office.

Prior to surgery, you will be asked to sign consent forms that detail the risks and complications of the procedure. This information should be similar to what you've already discussed with your surgeon.

Your surgeon will use a skin marker to confirm the incisions and make other marks to guide the surgery.

To make sure you are comfortable, you will receive **general anesthesia** (you are asleep and pain-free) or **intravenous sedation** (you are easy to awaken and pain-free) during your procedure. If general anesthesia is planned, you should not eat or drink for 8 to 12 hours before your surgery is scheduled. Some follow-up procedures in the surgeon's office require only **local anesthesia** (you are awake and pain-free).

When you awake from surgery, you will have gauze or bandages over your incision and a support bra or elastic bandage to reduce swelling and secure the

reconstructed breast. A small, thin tube or tubes (**surgical drains**) will be under your skin to help remove excess fluid or blood from the surgery site. Ask your doctor about bathing, showering, how to measure the fluid, and keep the drain clean. Be sure you understand how to take care of the drains and incisions.

Your doctor will prescribe pain medicine and antibiotics. Make sure your pain is controlled. You may have a **pain pump** that allows you to press a button to receive narcotic pain medication (a Patient Controlled Analgesia (PCA)) through a vein for one to three days after surgery. Sometimes, your surgeon will use a "**pain ball**" (non-narcotic) which slowly deflates, dripping pain medicine and a local anesthetic to the reconstructed area.

When the surgeon feels you are ready to be discharged, be sure to have someone drive you home and stay with you for the first night. Pillows can help you find a comfortable position in the car.

Visits to your plastic surgeon will be scheduled to remove the drains and make sure that you're recovering well. You cannot drive when you are taking narcotic pain medication, so you should arrange for someone to drive you.

RECOVERY

The first phase of the healing process for reconstructive surgery takes at least 4 – 6 weeks and you can expect to feel tired and sore. More than one operation may be required to complete the process or achieve the result you want.

Depending on your cancer diagnosis and level of treatment, complete recovery time will vary. Some women may need more than a year to feel completely healed and back to normal, while others need less time.

When a woman opts for immediate reconstruction (at the time of her mastectomy), she may recover 4-6 weeks faster than a woman who opts for delayed reconstruction (at a later date).

The shape and position of the new breast will improve as swelling diminishes. Eventually scars will fade but they will never completely disappear. Over time, some sensation may return to the reconstructed breast.

Although it is difficult to re-create the look and feel of a natural breast, most women are pleased with their new breast silhouette after reconstruction and their ability to look natural in clothing.

Finding support during this time is so important. It's very hard for women to engage and accept help, but now is the time. Not only are women dealing with cancer but the additional surgery creates a real need for emotional support.

— Marty Nason, Vice President of Programs,
The Wellness Community Valley/Ventura



*“I wish I knew more upfront about what problems were common, and then how to manage problems quickly. It really helped me to talk to other women who’ve been through this, and to read the books: **The Breast Reconstruction Book** by Kathy Steligo; and **Previvors** by Diana Roth Port.”*

— Corinne Schultz, prophylactic mastectomy
“Previvor”

6

Personal Considerations

FEELINGS OF LOSS

Many women will go through a process of mourning for their breast and its function after breast surgery. Your body image has been altered. How you feel about your body may change.

Allow yourself to grieve and know that it may take some time to come to terms with your new body. Over time, you can find that you develop a positive perspective and a new view of yourself as a woman.

The meaning of the loss of one's breast varies greatly from person to person. The important thing is to make a decision that makes sense to you. Take the time to ask yourself what the meaning of this loss is to you and for your significant others.

Replacing the lost breast with a reconstructed one at the time of surgery can minimize the sense of loss, because you will be rebuilding the breast that was removed. But, it is important to have realistic expectations.

YOUR SEXUALITY AND BODY IMAGE

Sexuality is closely related to your feelings about your body. It is complex, because sex may be the last thing on your mind during the emotional roller coaster of cancer diagnosis, treatment and recovery. Eventually, however, enjoying sexual intimacy will be on your mind.

The options of breast conservation and reconstruction give women a new sense of control over their treatment and are quite successful in helping women feel comfortable with their bodies again. Many women feel that plastic surgery can help reduce the visible signs of cancer. For women who don't choose reconstruction, there can be a period of readjustment to a new body image and a feeling of loss before feeling comfort and satisfaction with their bodies.

The effectiveness of breast conservation and reconstruction in preventing or reducing sexual problems after cancer is not clear. Any impact these options have on sexual experience is subtle and may relate more to a woman's feelings of being desirable than anything else.



My husband was very supportive through the entire process. His comment was: 'I didn't marry your breasts, I married you!' — Judy

Under any circumstance, women should pay attention to a loss of sexual desire or ability that may follow cancer treatment. Practical advice on lovemaking techniques by a clinician can help, and it's important to maintain an open attitude towards discussing loss and sexual issues to prevent anxiety and sadness as you search for ways to keep your sex life satisfying.

As with any life-changing issue, women with breast cancer can benefit from engaging in honest conversations about their adjusted body image and sex life. Though these conversations can be difficult or uncomfortable, there is often great relief associated with being open about physical, emotional, and sexual challenges associated with cancer — whether you talk with a professional, a partner or a friend.

For women who are single, finding yourself in a new intimate relationship can bring concerns about when to share information about your breast cancer with a partner, or how to reveal a scar on your breast. To get past these concerns, it can be especially helpful to talk with other breast cancer survivors.

In relationships, partners can be loving and supportive of a woman's changing body image by expressing acceptance and offering encouragement as a woman makes wardrobe or other changes to transition from a pre-cancer to a post-cancer body.

Some say that surviving cancer has helped them savor the beauty and joy they find in their families.

Tip: *ScarAway silicone scar sheets or a similar product might help reduce the sight of either new or old scars.*

EXERCISE CAN HELP

You've heard it before, and it's true. Regular exercise is shown to improve your physical functioning, self esteem, and quality of life after cancer. It will also help you manage any physical side effects from breast surgery and improve your mental outlook.

Breast surgeons will often recommend exercises to prepare your body for surgery and to aid in recovery after surgery and cancer treatment. You might also want to ask for a physical therapy evaluation if you are having radiation, an expander, or a flap procedure. Check if you are covered by insurance for physical therapy first. It helps to find a way to build more exercise into your life with anything that inspires you.

Try not to underestimate the value of exercise in your life after cancer. Incorporate a realistic exercise plan into your life now so that you can adjust as time goes on and you gain strength. If it's hard to start, think of it as a habit that you have to create in your life, to make your life better.

Exercise tailored to your level of energy (because your energy will be reduced in the short term after cancer treatment) will:

- Keep or improve your physical abilities
- Improve your self-esteem
- Improve your sexual functioning
- Lower risk of anxiety and depression
- Reduce impact from cancer treatment side effects such as fatigue and weakness
- Aid with sleeping
- Improve clarity with learning and thinking
- Lower risk of heart disease and osteoporosis and other health problems

Look for the **Cancer Transitions** program offered by the Cancer Support Community and **LIVESTRONG** to learn more about life after cancer. www.cancertransitions.org

FOLLOW-UP PLANS

Individuals who complete their treatment for cancer often fear that cancer will return. Reconstruction surgery poses no threat to women with respect to recurrence. Though some women fear that implants would hinder the detection of a recurrence, studies have shown that reconstruction does not cause breast cancer to return, nor do implants and flaps disguise the return of breast cancer or hide its detection.

It will be important to ask your doctor or nurse for a ‘survivorship care plan’ specifically for you, so you can know exactly what follow-up care you’ll need. For example, you should continue to have regular mammograms on a “healthy” breast and a reconstructed breast. Sometimes, women who have had a mastectomy aren’t asked to have a mammogram on the reconstructed breast. Breast changes or abnormalities will still be visible in a reconstructed breast if technologists are trained to move implants to obtain adequate radiology images.

On implant reconstructed breasts, the current FDA recommendation is to have a MRI once every three years to check the status of the implant. Often, a plastic surgeon will want to see you annually to make sure all is well with the reconstruction.



I had problems with a prosthesis because I'm very chesty. I think I'll have a reduction and go as small as possible. I'm very excited about it! — Peggy

For practical guidance to help you manage the costs of cancer treatment and recovery, order (at no cost!), **Frankly Speaking About Cancer: Coping with the Cost of Care** at www.cancersupportcommunity.org or by calling 1-888-793-9355

INSURANCE

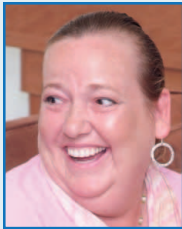
In most cases the **Federal Women's Health and Cancer Rights Act of 1998** requires that insurance companies cover the cost of reconstructive breast and nipple surgery for women who've undergone a mastectomy. This includes coverage for procedures on the uninvolved breast that restore and achieve symmetry so that your breasts match.

In some cases, an insurance company may not pay for a breast prosthesis and reconstructive surgery. This means, if you have been reimbursed for a breast prosthesis, then choose to have reconstruction at a later date, the insurance company may choose not to cover the costs of your breast reconstruction surgery. Be sure that you are completely informed about your insurance company's policies for coverage.

If you are not covered by an insurance plan, you can pursue several options to help cover the cost of reconstructive surgery. For example, university medical centers could have programs to support patient expenses at more reasonable rates; and in some cases state aid is available to support patients in need.

Contact the Patient Advocacy Foundation (www.patientadvocate.org) or My Hope Chest (www.myhopechest.org) to learn more about available financial resources.

7 *Your New Normal*



The cancer saved my life, personally, because I was able to stop and think about me. Something I never did before.

— Peggy

Because cancer exposes you to the fragility of life, it gives you an opportunity to do things you've left undone. You may wish to reconnect with family and friends, find new meanings for your life, and you might notice that you have acquired stronger coping skills and wisdom along the way.

So much happened so fast that you may not have had time to process what has occurred. Often, it is after treatment is complete that a flood of feelings emerge. This can surprise you and your whole support system. No one is prepared for this. Seeking support from places like the Cancer Support Community (with its Wellness Community and Gilda's Club affiliates), for example, can be extremely helpful at this time.

In the period after treatment, many people reflect on what they have been through and acknowledge the positive things that have come out of the cancer experience. Your task is to create a “new normal.”

The losses incurred by the cancer will become less painful and significant over time, and you will appreciate an increased sense of compassion and a different understanding of what’s really important in your life, for example.

Cancer may give you a greater sense of acceptance, and for some, a desire to “give back.” It will show you a different orientation to time – allowing you to live in the present and do things now rather than later. It may help you gain or have a greater appreciation for every moment and reprioritize the value of things in your life.



While my own family and friends have provided invaluable support and love to me, there’s a special connection I feel when I talk with other survivors who share the same experience as me.

— Sharishta

FIND STRENGTH IN SUPPORT

You may feel that support groups or counseling are for people with worse problems than you – or the idea of speaking with strangers would not be comfortable. The truth is, this is a time when supportive services could help you find ways to talk about and understand what you’re going through in a way that can only come from people who have experienced similar stressors.

Opening lines of communication with people who really understand what you are experiencing can help you improve your ability to cope, your ability to regain control over your situation, and your sense of security in having people you can count on.

Support can also be used to help you stay on track in terms of practical things like exercise, diet, and your overall health. For example, take advantage of friends who can help you get into an exercise routine to lose weight, improve your mental outlook, and help you find your new normal.



You know what's been most important to me? It was meeting people who were long term survivors at Gilda's Club. I am so honored to know these women. It just speaks to my heart and gives me pleasure because I know there is a future.

— Sandy

FINDING SUPPORT

There are many ways to get the support you need. Part of the challenge is accepting that you need support, and that it's okay.

The following organizations can connect you with support groups, informative resources, one-on-one counseling, online bulletin boards, or with other women who can speak from experience about breast cancer treatment or reconstruction.

- **Cancer Support Community**
www.cancersupportcommunity.org
888-793-9355
- **Bright Pink**
www.bebrightpink.org
BrightPink@bebrightpink.org
- **Facing Our Risk of Cancer Empowered**
www.facingourrisk.org
866-288-7475
- **Living Beyond Breast Cancer**
www.lbbc.org
888-753-5222
- **Young Survival Coalition**
www.youngsurvival.org
877-972-1011

8

Quick Reference: Reconstruction Options

TYPE OF RECONSTRUCTION	ELIGIBILITY	PROCESS AT TIME OF SURGERY	
<p>Saline/Silicone Implant - Direct to Implant/ One Stage Implant</p>	<ul style="list-style-type: none"> • Good for women who are slender and small-breasted or who do not wish to increase their bust size. • Smokers, obese women, or those who have had radiation therapy may not be eligible. 	<ul style="list-style-type: none"> • Implant is placed between layers of chest muscle under breast skin during the same surgery as the mastectomy. • ADM Acellular Dermis will usually be used. 	
<p>Saline/Silicone Implant - Two Stage Tissue Expander</p>	<ul style="list-style-type: none"> • Good for women with chest skin and muscles that are tight • Smokers or obese women may not be eligible. • Good for women who wish to be larger than their original size. 	<p>If chest skin and muscles are tight, reconstruction is done in 2 steps:</p> <ul style="list-style-type: none"> • First a tissue expander is placed in the mastectomy area. • The surgeon adds saline to increase the size of the expander at regular intervals in the office. • When the expander is the desired size, it is replaced with a smaller permanent implant in a second surgery. 	

	PROCESS AFTER CANCER TREATMENT	BENEFITS*	CONSIDERATIONS / RISKS
	<ul style="list-style-type: none"> • Radiation therapy may cause the implant to develop capsular contracture (get hard). • Remaining breast may be sized to match the reconstructed breast with implants. 	<ul style="list-style-type: none"> • Ask to see and touch your different implant options. • Ask to talk with other women who have had the procedure you are interested in. 	<ul style="list-style-type: none"> • Less surgery, anesthesia, pain and faster recovery than tissue flap procedures. • Risk of rupture, leak, deflation (1 in 10 in first 10 yrs.) • Silent rupture of a silicone implant may be detected only with MRI. • Implant may shift in place which may require an additional surgery. • Area around the implant may scar and harden (capsular contracture). • Infection after surgery is a risk. • Additional surgery may be needed for removal, replacement, revision or nipple reconstruction.
	<ul style="list-style-type: none"> • 2nd surgery (removal of the expander and placement of the implant) may be delayed until after chemotherapy and/or radiation therapy is completed. 	<ul style="list-style-type: none"> • Uses saline filled expander with valves that allow for expansion after surgery and can create the desired size. Skin stretches and droops in a natural curve. • Ask to see and touch your different implant options. • Less stress on the skin than in the direct to implant process. Saline can be removed if needed. • Gives women more time to think about the type of implant, final size and shape they desire. 	

* Under all circumstances ask to talk with other women who have had the procedure you are interested in.

BREAST RECONSTRUCTION OPTIONS (CONTINUED)

TYPE OF RECONSTRUCTION	ELIGIBILITY	PROCESS AT TIME OF SURGERY	
Oncoplastic Surgery	<ul style="list-style-type: none"> • Women with larger breasts must have clear margins from lumpectomy. 	<ul style="list-style-type: none"> • Typically prior to radiation therapy, could possibly be performed at lumpectomy surgery or after radiation completed. 	
TRAM (transverse rectus abdominus muscle) Flap – Pedicle Flap	<ul style="list-style-type: none"> • Women who are smokers, obese or very thin may not be eligible. • Women who have adequate abdominal fat may consider this option. 	<ul style="list-style-type: none"> • Skin, fat and muscle will be moved from the abdomen to chest area through a tunnel created by the surgeon under the skin. • Recovery from surgery may require several days in the hospital and several weeks off from work. 	

	PROCESS AFTER CANCER TREATMENT	BENEFITS*	CONSIDERATIONS /RISKS
	<ul style="list-style-type: none"> Radiation therapy usually done after oncoplastic surgery 	<ul style="list-style-type: none"> Using own breast tissue rearranged to fill in defect from lumpectomy or partial mastectomy, both breasts can be reduced and lifted if large breasts (basically a breast reduction). 	<ul style="list-style-type: none"> Radiation may cause affected breast to change, may become firmer or smaller risk for complication increased if performed after radiation therapy.
	<ul style="list-style-type: none"> If radiation or chemotherapy is recommended after mastectomy, TRAM flap may be delayed until after treatment is complete. With a skin sparing mastectomy, an implant or tissue expander may be used temporarily to keep the skin stretched. 	<ul style="list-style-type: none"> Since the reconstructed breast is made from your own skin and fat it will be more similar to natural breast tissue. Your tummy will be flatter although the scar is higher than a "tummy tuck" scar (may change the look of your belly button). 	<ul style="list-style-type: none"> TRAM surgery and recovery times take longer than implant surgery. There will be 2 surgical sites and 2 scars. Abdominal hernia and abdominal bulge is possible due to the removal of supportive abdominal muscle. Flap may die and have to be removed. A pedicle flap is less likely to completely fail than a free flap. There is a risk for infection and problems with healing. You will need additional surgery to create a nipple and areola, and possibly additional surgery to shape the flap.

* Under all circumstances ask to talk with other women who have had the procedure you are interested in.

BREAST RECONSTRUCTION OPTIONS (CONTINUED)

TYPE OF RECONSTRUCTION	ELIGIBILITY	PROCESS AT TIME OF SURGERY	
<p>TRAM (transverse rectus abdominus muscle) Flap – Free Flap</p>	<ul style="list-style-type: none"> • Women who are smokers, obese or very thin may not be eligible. 	<ul style="list-style-type: none"> • A section of skin, fat, muscle and blood vessels are cut free from their location in the abdomen, relocated to the chest area and reconnected to the blood supply using microsurgery. • Surgery can take many hours. 	
<p>Latissimus Dorsi Flap (Lat Flap)</p>	<ul style="list-style-type: none"> • Women who have had radiation therapy and are not candidates for tissue expansion may consider this option. • Best for women with average amounts of body fat and small-to-medium-size breasts. • Women with vascular disease, diabetes or connective tissue disease may not be eligible. Women who are overweight or obese and smokers may not be eligible. 	<ul style="list-style-type: none"> • Skin and muscle will be moved from the upper back to the mastectomy area through a tunnel created by the surgeon under your skin. An implant is placed under the flap to create the desired volume. 	

	PROCESS AFTER CANCER TREATMENT	BENEFITS*	CONSIDERATIONS / RISKS
	<ul style="list-style-type: none"> If radiation or chemotherapy is recommended after mastectomy, TRAM flap may be delayed until after treatment is complete. 	<ul style="list-style-type: none"> Feels like a natural breast and is warm and soft because of good circulation. Moves like your natural breast because it is also fat tissue. Because abdominal tissues are used, you will also have a tummy tuck. Should last for your lifetime. 	<ul style="list-style-type: none"> TRAM surgery and recovery takes longer than implant surgery. Surgical time for a TRAM free flap is longer than for a pedicle flap. You will have 2 surgical sites and 2 scars. Abdominal hernia and abdominal bulge is possible with the removal of abdomen muscles. Flap may die and have to be removed. A free flap is more likely to fail than a pedicle flap (5% failure rate). There is a risk for infection and healing problems. You will need additional surgery to create a nipple and areola, and to shape the flap.
	<ul style="list-style-type: none"> If radiation or chemotherapy is recommended after mastectomy, Latissimus Dorsi Flap may be delayed until after treatment is complete. 	<ul style="list-style-type: none"> Transplanted skin will be a close color match for your breast skin. The breast will feel warm and flexible. 	<ul style="list-style-type: none"> You will have 2 surgical sites and 2 scars. Some women experience weakness in the back, shoulder and arm muscles and require physical therapy. There is a risk for infection and problems with healing. You will need additional surgery to create a nipple and areola. Since an implant is placed there are similar risks to implant surgery such as deflation, capsular contracture etc.

* Under all circumstances ask to talk with other women who have had the procedure you are interested in.

BREAST RECONSTRUCTION OPTIONS (CONTINUED)

TYPE OF RECONSTRUCTION	ELIGIBILITY	PROCESS AT TIME OF SURGERY	
<p>DIEP (deep inferior epigastric perforator) Flap</p>	<ul style="list-style-type: none"> • Women who are smokers, very thin or have already had a procedure to remove abdominal skin and fat are not eligible. 	<ul style="list-style-type: none"> • Skin, fat and blood vessels are moved from the upper abdomen to the chest area and then reconnected to the blood supply using microsurgery. A small implant can be placed under the tissue flap if necessary. • Surgery can take many hours. 	
<p>SIEA (superior inferior epigastric artery) Flap</p>	<ul style="list-style-type: none"> • Women who are smokers, very thin or have already had a procedure to remove abdominal skin and fat are not eligible. 	<ul style="list-style-type: none"> • Skin, fat and blood vessels are moved from the lower abdomen to the chest area and then reconnected to the blood supply using microsurgery. • Surgery can take many hours. 	

	PROCESS AFTER CANCER TREATMENT	BENEFITS*	CONSIDERATIONS / RISKS
	<ul style="list-style-type: none"> If radiation or chemotherapy is recommended after mastectomy, DIEP flap may be delayed until after treatment is complete. 	<ul style="list-style-type: none"> No muscle is removed so there is minimal risk of an abdominal hernia (unlike TRAM flap). There may be less pain, faster recovery than TRAM flap. Similar to a TRAM flap your tummy will be flatter. 	<ul style="list-style-type: none"> More time in surgery than TRAM flap. You will have 2 surgical sites and 2 scars. If the procedure fails, the flap will die and must be removed There is a risk for infection and problems with healing. You will need additional surgery to create a nipple and areola.
	<ul style="list-style-type: none"> If radiation or chemotherapy is recommended after mastectomy, SIEA flap may be delayed until after treatment is complete. 	<ul style="list-style-type: none"> SIEA blood vessels are not located within muscle so abdominal muscles are never disturbed. There is minimal risk of an abdominal hernia (unlike TRAM flap). Less pain, faster recovery than TRAM flap. Similar to a TRAM flap your tummy will be flatter. 	<ul style="list-style-type: none"> There is a risk for infection and problems with healing. You will need additional surgery to create a nipple and areola. Slightly higher risk of partial flap loss than DIEP. Not all patients are good candidates, depending on their vascular anatomy.

* Under all circumstances ask to talk with other women who have had the procedure you are interested in.

BREAST RECONSTRUCTION OPTIONS (CONTINUED)

TYPE OF RECONSTRUCTION	ELIGIBILITY	PROCESS AT TIME OF SURGERY	
IGAP (inferior gluteal artery perforator) Flap	<ul style="list-style-type: none"> • Women without adequate abdominal fat are good candidates for IGAP. • Smokers and women who have previously had lower buttock skin and fat removed or have had liposuction on the lower buttock are not eligible. 	<ul style="list-style-type: none"> • Fat, skin and blood vessels are removed from the lower buttock to the chest area and then reconnected to the blood supply using microsurgery. • Surgery can take many hours. 	
SGAP (superior gluteal artery perforator) Flap	<ul style="list-style-type: none"> • Women without adequate abdominal fat are good candidates. • Smokers and women who have previously had upper buttock skin and fat removed or have had liposuction on the upper buttock are not eligible. 	<ul style="list-style-type: none"> • Fat, skin and blood vessels are removed from the upper buttock to the chest area and then reconnected to the blood supply using microsurgery. • Surgery can take many hours. 	
TUG (transverse upper gracilis) Flap	<ul style="list-style-type: none"> • Women without adequate abdominal fat are good candidates. • Smokers and women who have previously had upper buttock skin and fat removed or have had liposuction on the upper buttock are not eligible. 	<ul style="list-style-type: none"> • Fat, skin, muscle, and blood vessels are moved from the upper inner thigh to the chest, then reconnected to the blood supply using microsurgery. • Surgery can take many hours. 	

	PROCESS AFTER CANCER TREATMENT	BENEFITS*	CONSIDERATIONS / RISKS
	<ul style="list-style-type: none"> If radiation or chemotherapy is recommended after mastectomy, IGAP flap may be delayed until after treatment is complete. 	<ul style="list-style-type: none"> No muscle is cut or moved resulting in quicker recovery time. Buttock lift results from removal of gluteal skin and fat. 	<ul style="list-style-type: none"> There will be 2 surgical sites and 2 scars. If the procedure fails, the flap will die and must be removed – new reconstruction may not be done for 6-12 months. There is a risk for infection and problems with healing. You will need additional surgery to create a nipple and areola.
	<ul style="list-style-type: none"> If radiation or chemotherapy is recommended after mastectomy, SGAP flap may be delayed until after treatment is complete. 	<ul style="list-style-type: none"> No muscle is cut or moved resulting in quicker recovery time. Buttock lift results from removal of gluteal skin and fat. 	<ul style="list-style-type: none"> There will be 2 surgical sites and 2 scars. If the procedure fails, the flap will die and must be removed – new reconstruction may not be done for 6-12 months. There is a risk for infection and problems with healing. You will need additional surgery to create a nipple and areola.
	<ul style="list-style-type: none"> If radiation or chemotherapy is recommended after mastectomy, TUG flap may be delayed until after treatment is complete. 	<ul style="list-style-type: none"> Inner thigh lift results from this surgery. 	<ul style="list-style-type: none"> There will be 2 surgical sites and 2 scars. If the procedure fails, the flap will die and must be removed.

* Under all circumstances ask to talk with other women who have had the procedure you are interested in.

NIPPLE AND AREOLA OPTIONS

TYPES	PROCEDURE	BENEFITS	
Nipple/Areola Reconstruction	<ul style="list-style-type: none"> • Nipple can be made with tissue from the reconstructed breast, by sharing part of the nipple from the other breast (composite nipple). • ADM may be implanted to maintain projection. • The areola is most commonly reconstructed with a skin graft from another part of the body. • 3-12 months after breast reconstruction, typically the last step of the reconstruction process. 	<ul style="list-style-type: none"> • Completes the reconstruction process. • Breast will look more like a natural breast. 	
Nipple-Sparing Mastectomy	<ul style="list-style-type: none"> • Women with small, early stage cancer located in outer part of breast (distant from nipple) and with no skin involvement may have nipple and areola left in place when breast tissue is removed. 	<ul style="list-style-type: none"> • Patient maintains her own nipple although it could be flatter and not sensitive. 	
Adhesive Nipples	<ul style="list-style-type: none"> • Latex nipples are held in place with fluid adhesive. • Silicone nipples don't require 'glue.' 	<ul style="list-style-type: none"> • Easy to remove and reusable. • Come in different colors. 	
Nipple Tattoo	<ul style="list-style-type: none"> • A tattooing process called micropigmentation is used to create the appearance of a nipple 3-6 months after breast reconstruction. • Colors are mixed to match the shade desired. • Takes less than an hour. 	<ul style="list-style-type: none"> • Completes the breast reconstruction process. • Can cover scarring. • Adds pigment to create a natural look. 	

	RISKS	CONSIDERATIONS
	<ul style="list-style-type: none"> • Tenderness at site of tissue harvest. 	<ul style="list-style-type: none"> • Nipple does not have sensation of original nipple • Two hour, outpatient procedure. • Separate office visit to tattoo coloring of nipple. • To ensure the skin graft stays, a bolster dressing is worn for several days which cannot get wet. • Minimal pain.
	<ul style="list-style-type: none"> • Nerves are cut so there is little or no sensation in nipple. Inadequate blood supply can wither or deform the nipple. • Patients should ask their breast surgeon if there will be an increased risk of the cancer recurring. 	<ul style="list-style-type: none"> • MD may give nipple a dose of radiation during or after surgery to reduce risk of cancer recurrence. • May not be possible or may not be possible in women with large breasts. • Surgery is becoming widely available.
		<ul style="list-style-type: none"> • Both latex and silicone can be custom-made to match your remaining nipple.
	<ul style="list-style-type: none"> • Tenderness or pain varies. • Scarring or infection can occur. 	<ul style="list-style-type: none"> • Nipple tattooing does not create sensation in the area. • May require more than one session to achieve desired color. • Color fades over time; process may need to be repeated.

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Glossary & Resources

Acellular Dermis - human tissue used for coverage, support and stabilization of the implant and expander

Areola reconstruction - use of tattooing to re-create the appearance of the areola (colored area around the nipple)

BRCA1 and BRCA2 - genetic mutations that lead to an increased risk of developing breast and ovarian cancer

Breast form or prosthesis - a silicone, foam rubber, fiberfill or cotton breast-like shape, worn inside the bra or attached to the body with adhesive strips, to re-create the form and weight of the breast

Breast-conserving surgery - surgery to remove breast cancer and a small amount of surrounding tissue without removing the entire breast; see lumpectomy, partial mastectomy and segmental mastectomy

Breast reconstruction - surgery performed after mastectomy to rebuild the breast, restoring its shape and size through use of an implant or tissue from another part of the body

Capsular contracture - formation of scar tissue around a breast implant, which can lead to pain, hardening and a distorted shape

Cell enhanced breast reconstruction - surgical procedure to inject fat tissue, rich in stem cells, which has been subjected to a special process to enhance its ability to adapt to a new site, into a lumpectomy site to restore the full curve of the breast

DIEP (deep inferior epigastric artery perforator) flap - a free flap surgery using fat and skin, but not muscle, from the upper abdominal area to reconstruct the breast

Direct to implant - surgery with an implant performed in one stage, at the same time as a mastectomy; also called single stage reconstruction

Drain - thin tube placed at surgical site to remove excess fluid and blood; also called surgical drain

Expander to Implant - surgery performed in two steps, using a tissue expander first to increase the space between the skin and chest muscle, followed by placement of an implant; also called two-stage reconstruction or two-stage delayed reconstruction

Free flap – surgical procedure where tissue is cut away from its original location and attached to a new blood supply in the chest area

Gluteal free flap – surgery using tissue from the buttocks, to recreate the shape of the breast; see also IGAP and SGAP

IGAP (inferior gluteal artery perforator) flap – free flap surgery using fat and skin from the lower buttock to rebuild the breast

Immediate reconstruction – surgery to reconstruct the breast occurs at the same time as a mastectomy

Implant – silicone form, filled with either saline (sterile salt water) or silicone gel, used in breast reconstruction to restore the shape of the breast

Latissimus dorsi flap – surgery using tissue from the upper back, which is tunneled under the skin to the breast area, creating a pocket for an implant

Lumpectomy – surgery to remove a breast tumor ('lump') and a small amount of surrounding normal tissue

Lymph node dissection – removal of lymph nodes under the arm for biopsy

Microsurgery – use of an operating microscope to enhance reconnection of blood vessels and nerves

Modified radical mastectomy – surgery to remove the breast, many lymph nodes, the lining over the chest muscles and part of the chest wall muscles

Nipple reconstruction – surgery to recreate a nipple using tissue from the reconstructed breast, opposite nipple, abdomen, eyelid, groin, inner thigh or buttocks

Nipple-sparing mastectomy – surgery where nipple is not removed, performed when cancer is at an early stage, located far from the nipple

Oncoplastic surgery – rearrangement of breast tissue after lumpectomy and symmetry procedure on other breast (example, breast reduction)

Partial mastectomy – surgery to remove the part of the breast where cancer is found and some surrounding normal tissue

Pedicle flap – tissue remains attached to its original blood supply and is tunneled under the skin to the breast area

Prophylactic mastectomy – surgery to remove a non-cancerous breast to prevent cancer when genetic risk is high

Radical mastectomy/Halsted radical mastectomy – surgery to remove the breast, chest wall muscles under the breast and all the lymph nodes

Segmental mastectomy – see partial mastectomy

SGAP (superior gluteal artery perforator) flap – free flap surgery using fat and skin from the upper buttock to reconstruct the breast

SIEA (superficial inferior epigastric artery) flap – free flap surgery using skin and fat from the lower abdominal area to rebuild the breast

Tissue expander – balloon-like form placed under the skin and muscle where the breast was removed; can be gradually inflated to allow space for a permanent implant

Tissue flap procedure – surgery using tissue from another part of the body (abdomen, back, thighs or buttocks) to rebuild the breast

Total mastectomy – surgery to remove the breast and some lymph nodes

TRAM (transverse rectus abdominis muscle) flap – surgery using tissue from the abdomen, including skin, fat, blood vessels and at least one abdominal muscle, to rebuild the breast

Two-stage reconstruction or two-stage delayed reconstruction – see expander to implant

ADDITIONAL RESOURCES

In addition to the organizations listed as partners in this booklet, you may also want to seek information from:

www.yourbreastoptions.com

provides comprehensive information about breast health, breast cancer awareness and reconstruction options, including testimonials

www.myhopechest.org

a foundation dedicated to finding resources for women who wish to undergo reconstruction after cancer

www.breastreconstruction.org

a comprehensive online resource focused on breast reconstruction

www.cancer.org

the American Cancer Society, with active bulletin boards and in-depth online resources

www.breastcancer.org

covering many aspects of breast cancer and its treatment, including information about reconstruction

www.fertilehope.org

helps cancer patients facing the risk of infertility

EDITORS & EXPERTS

Sharon Adell, RN, NP, MN, CBHN
Providence Saint Joseph Medical Center, CA

Marni Amsellem, PhD
Clinical Psychologist

Elyse Spatz Caplan
LBBC

Susan E. Downey, MD
Plastic and Reconstructive Surgery, CA

Lisa Grollman, RN
Georgetown University Hospital, DC

Stacy Lewis
YSC

Linda Miller, RN, MSN, OCN
Georgetown University Hospital, DC

Amy Mlodzianowski, OSW
Gilda's Club, NY

Marty Nason, RN, MN, CSN
The Wellness Community Valley/Ventura, CA

Barbara Pfeiffer
FORCE

Leif Rogers, M.D., F.A.C.S.
Beverly Hills, CA

Corinne Schultz
Previvor

Melissa Snyder
Bright Pink

Erica H. Weiss, MPH, MSUP
Managing Editor

DESIGN & PHOTOGRAPHY

Kessler Design Group, Ltd., Design
June Greenspan, Photography
Ginny Rickay, Photography

THE CANCER SUPPORT COMMUNITY

The Cancer Support Community is likely the largest psycho-social support organization in the world with a mission to ensure that all people impacted by cancer are empowered by knowledge, strengthened by action, and sustained by community.

BRIGHT PINK

Bright Pink believes in the beauty and strength of women. It exists to enlighten and empower high risk individuals to take control of their breast and ovarian health by providing education, support and a sense of community for a better, brighter future.

FACING OUR RISK OF CANCER EMPOWERED (FORCE)

FORCE is the only international nonprofit organization devoted to improving the lives of individuals and families affected by hereditary breast and ovarian cancer or a BRCA mutation.

LIVING BEYOND BREAST CANCER (LBBC)

Living Beyond Breast Cancer's mission is to empower all women affected by breast cancer to live as long as possible with the best quality of life.

YOUNG SURVIVAL COALITION (YSC)

Young Survival Coalition (YSC) is the premier international organization dedicated to the critical issues unique to young women and breast cancer.



The Cancer Support Community and our partners provide this information as a service. This publication is not intended to take the place of medical care or the advice of your doctor. We strongly suggest consulting your doctor or other health care professional to answer questions and learn more.

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