

Guidelines for Victims of Flat Denial: Navigating the Aftermath

Published by *Not Putting on a Shirt*

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Questions? Email us at NotPuttingonaShirt@gmail.com

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What is “Flat Denial”?

"Flat denial" - when a mastectomy patients' wishes to have a smooth flat chest after their surgery are denied by the unilateral actions of their surgeon(s), either intentionally despite technical competence, or by default through incompetence. These surgeons are either unwilling or unable to produce the desired result for the patient and fail to fully inform the patient of these facts - and critically, in violation of their Hippocratic Oath, fail to refer her to a willing and competent colleague. Their actions leave the patient with an unacceptable result that requires additional surgeries to fix. This can happen to a patient during her initial surgery, as well as during explant and flap removal procedures to "deconstruct" and go flat.

For articles and media coverage about flat denial, to access the private Facebook support group exclusively for victims of flat denial, to share your story publicly, or to contact us directly: www.NotPuttingonaShirt.org

Our Message to Victims

Did you decide against breast reconstruction, and agree on a flat closure in consult with your surgeon prior to the operation? Did you wake up to a result that is nowhere near “flat”? It may be a moderate amount of excess tissue that was left, or it may rise to the level of what’s called a “skin-sparing” procedure which essentially leaves “deflated breasts” to facilitate implant reconstruction. And/or it may be that the closure was done carelessly and inexpertly, resulting in puckering, folds/creases, significant “dog ears,” and other uncomfortable and unsightly not-flat outcomes. In either case, if you suspect that you are a victim of flat denial, we are here to tell you: **this is NOT your fault, and you’re not alone.** This happens to women all the time, unfortunately. And until we can put a stop to it, women are going to have to deal with the aftermath. *Not Putting on a Shirt* has written these guidelines based on our experience with flat denial. We hope you find them helpful. If you have any questions, concerns or suggestions, please email us at NotPuttingonaShirt@gmail.com

Flat denial is a traumatic experience. In many if not most cases, it rises to the level of medical assault and battery. Feelings of betrayal, violation, sadness, rage, regret, panic and despair are all normal after an assault. If you find these feelings to be lingering, severe and/or debilitating, please seek help from a qualified mental health professional. The first resource for locating such a professional is the social worker or nurse navigator at your medical oncologist’s facility. Even if you aren’t experiencing extreme distress, speaking with a therapist or social worker who specializes in cancer related issues can be very helpful in processing what has happened to you, as well as in deciding how to move forward. Many localities have non-profit cancer community centers that offer support groups and sometimes even individual counselling at low or no cost to cancer patients. You can also start by calling your national cancer society’s hotline or visiting their website.

United States	Canada
The American Cancer Society	The Canadian Cancer Society
1-800-227-2345 (24 hour hotline)	1-888-939-3333 (M-F hotline)
www.cancer.org	www.cancer.ca

Please know that an unacceptable mastectomy result can almost always be improved, often dramatically, with what’s known as “revision surgery.” These surgeries are sometimes done by a plastic surgeon, sometimes by a general or breast surgeon, and the goal is to remove all remaining excess tissue and “clean up” the surgical site to create a smooth, flat, final result. Oftentimes these surgeries don’t require drains, and the healing period is typically

much quicker than with the original mastectomy. With revision, it's less of an amputation and more of a nip-and-tuck. **We don't want to minimize the fact that revision is an additional surgery - only to give you the assurance that what was done to you in most cases need not be permanent.**

Many women who choose to go flat, do so in order to be "one and done," with the overriding goal of avoiding additional surgeries. It can be disheartening, even downright depressing, to be forced into the position of facing additional surgery that could have been avoided. Accepting that you have lost your chance to be done in one surgery, is a grief process, and will involve all the emotions that entails. You may decide that revision surgery is not worth the risk - many women do. Whatever you ultimately decided... this is not something you have to decide RIGHT NOW. Revision surgery can be performed months or years in the future. **You have time to think about what's best for you.** Especially if you are facing radiation, most surgeons advise waiting at least a year to have your revision surgery.

Insurance companies sometimes balk and initially refuse to cover revision surgery. If your new surgeon's office knows how to code for the procedure correctly, this should not be a problem. *Not Putting on a Shirt* is working, in collaboration with other parties, to formulate guidelines to help surgeons to code successfully for revision surgery.

First: Get Your Medical Records and Take Pictures

If you suspect you may have been victimized, please don't hesitate to request a copy of your medical record, including consultation notes and post-operative reports. This way, in the event your surgeon decides to cover his or her tracks by altering the record, you already have the originals. You can usually request your records by calling the surgeon's office, or by calling your insurance company. The rule of thumb when you have been victimized by a medical professional is to **document everything**. Taking pictures of your chest at regular intervals (once every month, for example) is also an important step in ensuring that your experience is documented. Many surgeons will deny leaving excess tissue, and/or claim "it'll tighten up" (it won't - skin stretches over time, it doesn't contract). It helps to have your healing process visually documented.

It will likely be very difficult for you to look at your post-op chest. This is not what you chose to look like after your mastectomy, and for most women who experience flat denial, that is extremely upsetting. Please try to remember that even when a woman's wishes are respected, the sudden drastic change in the appearance of your own body can be shocking and traumatic. Surgical drains and incisions are uncomfortable and not easy to look at either. These feelings are normal, and you won't always feel this upset looking at yourself. But it will take time.

Take Care of Yourself First

Now is the time to take care of YOU. After you have made sure you have proper documentation, your next task is to take care of your own physical and emotional needs. When faced with a decision, whether it's dealing with your medical trauma specifically or just in life in general, ask yourself, does this protect my interests and well-being? You have just experienced a serious additional trauma on top of breast cancer treatment, which in itself is traumatic. Be gentle with yourself and put your own needs first. Your first priority right now is healing from the mastectomy. This is an amputation. It's not a cosmetic surgery. You will need at least 2-4 weeks if not longer to even begin to resume normal daily activities, and you will need rest, hydration, and proper nutrition in order to heal properly.

If you are recently post-op and still need surgical aftercare (drains, follow-up exams, wound care management), you will probably feel inclined to find a new surgeon. Many women do not want to continue to see the same surgeon that victimized them and feel that continuing to see that surgeon re-traumatizes them. We recommend finding your new surgeon at a new facility to avoid retaliation and ensure that your aftercare isn't compromised. Unfortunately, it can

sometimes take weeks to get in to see a new surgeon. If you are able, cast a wide net by calling multiple surgeons and seeing who can get you in the soonest. You can also email NotPuttingonaShirt@gmail.com to access the list we curate.

You may wish to wait until after your surgical pathology report comes back to fire your original surgeon, if you wish to speak with that surgeon about the results. This usually takes 1-2 weeks. This report will tell you what was found in the tissues that were removed during the mastectomy (including any lymph nodes if that was deemed necessary) and will help determine your surgical, medical, and radiation oncologists' treatment plan for you moving forward.

- **Surgical Aftercare.** In most cases, with mastectomy, there is no need for additional surgery to obtain clear margins. Clear margins means the surgeon was able to remove all of the tumor(s) and cancerous nodes along with a healthy border of cancer-free tissue, to ensure they got all of the cancer. Occasionally, patients do need an additional surgery to get clear margins. The surgical pathology report will determine that.
- **Medical and Radiation Oncology Care.** If you had chemotherapy prior to surgery, the report will show whether or not there was any invasive cancer remaining, and where the remaining cancer cells were. If you did not have neoadjuvant chemotherapy, the report will help your medical and radiation oncologists whether or not you will need chemotherapy or other treatments (radiation, hormone therapy).

When you do go looking for a new surgeon... what type of surgeon? Plastic surgeon or surgical oncologist (usually a breast surgeon or a general surgeon)? If it was your surgical oncologist who victimized you, you will definitely need to find a new surgical oncologist first. **Sticking to your cancer treatment plan and getting appropriate cancer care should always be your #1 concern - and you can only do that under the care of a surgical oncologist.** You may be facing chemotherapy, radiation, ongoing surgical drain aftercare, complications from the mastectomy, or other pressing medical concerns. **Never delay radiation or other cancer treatments in the hopes of getting a scar revision first - it's not worth the risk.**

Questions to Ask Your New Surgeon(s):

When you speak with the new surgeon(s), you will want to explain what happened to you. **Try to stick to the facts.** You agreed on a flat closure, your original surgeon clearly didn't honor that agreement, and now you feel that you can't trust them, and are looking for another surgeon to provide surgical oncology care (or plastics care) for you moving forward. It's in your interest to stay calm and collected, even though that may be difficult. It may help to write down what you plan to say so that you don't have to "perform" at the consultation. It may also help to bring a trusted friend or partner, not only as a witness, but as emotional support for you... and, frankly, the presence of a second person can help ensure that the surgeon takes you seriously. It can help to review the brochures on flat denial at our blog, www.NotPuttingonaShirt.org in advance of the consultation, so that you feel confident going in.

Evaluate their response to your story. The way the surgeon responds when you tell your story, is your first clue as to whether they are going to be trustworthy. A surgeon who tries to make excuses, seems to blame you for what happened, or generally treats you unkindly or with disregard, is not someone you will want to trust with your body. Their response should be one of care and concern. They should be able to explain to you in detail how they will proceed to ensure you an acceptable flat result:

- **Will they bring on the team, or refer you to a plastic surgeon? If not, proceed with asking very specific questions about their plan. If so, ask the same questions of the plastic surgeon.**
- Are they familiar with oncoplasty and/or flat closure techniques?
- Have they performed flat scar revisions for previous patients? Ask to see pictures of their work.

- How specifically will they ensure that YOU get a flat result, given whatever specific challenges you face - severe dog ears, scarring and tissue damage from radiation after your original surgery, co-existing health conditions like lymphedema or diabetes, “excess” body fat (more tissue can require additional time in the OR), special concerns you may have about scar placement, and so on.
- Will they sit you up to mark the site prior to surgery, to account for gravity's effect on the tissues? If not, how do they “check” their final result”?
- Will they be going in through the original scar? If not, what incision pattern will work best for your body, to achieve a flat result? There are various patterns including T, Y, fishtail, continuous between both mastectomy sites, and more.
- How do they close the incision, with staples, stitches, glue?
- You may also want to ask if it's likely you will need surgical drains, just so you know what to expect.
- **Does their office know how to properly code for scar revision so that insurance covers it?**

The final challenge is coding for the revision surgery so that insurance will cover it. This can be a thorny area. It's ultimately the surgeon's office's responsibility to solve this problem, but many surgeons - even plastic surgeons - are not experienced in this area. Unfortunately, until we can get the law amended, this will continue to be a stumbling block. **If the surgeon tells you your revision won't be covered... it may be time to find a new surgeon!**

Dressing Your Body After Flat Denial

You may have been looking forward to showing off your new flat chest, or you may be a more private person. Some women are surprised at how their new flatness changes their body image for the better! **But when you've been a victim of flat denial, you can feel stuck somewhere you never wanted to be. No breasts... but not flat, either.** Feelings of disgust, humiliation, sadness, anger and despair are all normal responses to the type of violation of your body's integrity that flat denial represents. It might be hard for you to even look in the mirror at first. That's ok. It won't always be this difficult. If you find these feelings to be extreme or debilitating, please seek help from a qualified mental health professional. Part of healing is taking care of your emotional well-being.

Many women left with excess tissue, choose to wear compression garments to contain the tissue and create a more flat contour. Other women find compression uncomfortable and prefer to wear baggy clothing and/or layers to camouflage the lumps and bumps. And some women choose to wear prostheses in the interim. Every woman is different. You should wear what makes you feel the most comfortable overall. And this might change over time. You might feel better with compression at first, and then find some styles of tops that allow you to ditch the compression. Clothes shopping after mastectomy can be emotionally exhausting, even more so when you've been a victim of flat denial and are stuck “in limbo” as some women have described it. Be gentle and patient with yourself. You will get through this!

Getting Justice

Documenting Your Experience is CRITICAL. Collect all your documentation in one place (a folder, binder, etc.) You have your medical record. You have your pictures of your post-op chest. Now you can make your timeline - this is a running list of actions you have taken and communications you have sent or received, regarding your flat denial

experience. When finding the following entities (law firms, medical board, etc.) in your search for justice, keep a record of each entity you contact, what was discussed, and their response. Keep a record of any and all communications you have with the hospital, the old surgeon, or any other entities involved. Print everything out with dates. **[You will soon be able to find form letters for writing to these entities - those are in progress currently.]**

Contact Attorneys. If you think you might want to pursue legal action against the surgeon who violated your consent, the time to speak with an attorney is ASAP. Many states have shockingly short statutes of limitations for medical malpractice - sometimes as short as one year. At one year post-op, many breast cancer patients are still in active treatment, and don't have the capacity to pursue legal action. If you are able, call several medical malpractice and/or personal injury firms in your area (specifically, in the geographic area where this happened you).

When you speak with attorneys, stick to the facts. Write down your story and then try to pare it down to an executive summary, or "elevator pitch," that you can tell over the phone. Stress that you have documentation of everything. It can be something like this:

You were subjected to what you believe to be medical battery. You consented to a flat closure, and your surgeon did something completely different against your will. In addition to emotional distress, this necessitates additional surgery to fix, which is always risky.

Contact Other Entities. Next, you can start contacting other entities to inform them of the malpractice that was perpetrated against you. Please note that this list may not be comprehensive. The list is in the order in which it would be prudent to initiate contact. If you can, retain an attorney first.

- **Hospital Ombudsman**

You will want to file a complaint with the hospital's Ombudsman office as soon as you are able. We recommend retaining an attorney first and taking their advice, but if you are unable to find an attorney (as many women have been to date), you should still file a complaint with the Ombudsman. This is mainly to show that you are acting in good faith, giving the hospital a chance to address the problem. In our experience, unfortunately, hospitals will attempt to cover up what happened. They don't want to admit malpractice because it opens them up to a lawsuit. **Remember to ask for copies of ALL correspondence.**

- **Hospital Ethics Board**

This letter is simply a notification of the Ombudsman proceedings and to ensure that the ethicists hear your story. The ethics board typically will not involve itself to help you. But you may have an impact on the individuals and hopefully that will at least lead to discussions within the hospital about what you experienced. Print out any email correspondence from the ethics board and keep it in your folder.

- **Hospital Executive Administration**

This letter will be sent straight to the top (CEO), and copy the other relevant entities below (Surgery Department Head, Patient Experience Office). You may or may not receive a response to this letter.

- **State Medical Board**

Every state has a medical board which licenses doctors and other medical professionals. They field complaints of misconduct and pursue disciplinary action as they see fit. Unfortunately, this is not a transparent process. After your initial discussion (usually over the phone, or in person) with the investigator, you likely won't hear back from them until they make a decision on your case. The important thing here is to document that you have taken the proper steps to get the malpractice addressed, notified the proper entities, and can proceed with your legal case.

- **Your Insurance Company**

You may want to notify your insurance company that your surgeon's unethical actions (operating without informed consent) have necessitated additional surgery. On this basis, the insurance company may elect to reduce or rescind their reimbursement for the procedure. Insurance companies interests are aligned with patients who want to go flat - they save money when we only require a single surgery.

- **State Department of Insurance Fraud**

You may also want to notify your state's insurance fraud task force of the situation. Of course, there's no way for you as the patient to know for sure if fraud occurred, but it stands to reason that a surgeon acting against the patient's will to ensure a repeat surgery, and therefore a repeat reimbursement by the insurance company, may have had a fraudulent motive. When you file this notification, the task force can investigate. As with the state medical board, this is not a transparent process, so once you initiate the complaint you may not hear back for months.

Afterword

As the founder of Not Putting on a Shirt, and a victim of flat denial myself, I am sorry this has happened to you, and I hope these guidelines have been of some use or at least of some small comfort during this time. My goal at NPoaS is to work to put an end to flat denial so that these guidelines will one day be obsolete. Part of that work is ensuring that surgeons and hospitals know that we, the patients, WILL hold them accountable for treating women who choose to go flat with the same honesty, care, respect and dignity afforded to our reconstructing sisters. We will NOT tolerate flat denial. Documenting our experiences of flat denial, I believe, will play a key role in the process of characterizing how and why flat denial happens, and in facilitating formulation of protocols and resources that will make a difference for patients. Please feel free to share this document with anyone you feel could benefit from it.

For more information, or if you have questions, comments or suggestions, please contact us!

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Solidarity, and best of luck!

Kim Bowles

Founder, *Not Putting on a Shirt*