Joining FORCES Against Hereditary Cancer

Post-mastectomy Recovery and Lymphedema

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What Can You Expect?

Mastectomy
- Incision(s) create scar(s)
- Removes breast skin (no immediate reconstruction)
- Preserves most breast skin (immediate reconstruction)
- Removes nipple/areola vs nipple/areola-sparing
- Removes breast tissue
- Severs sensory nerves
- Lymph nodes may also be removed

What Can You Expect?

Recovery depends on:
- Type of mastectomy
  - unilateral or bilateral
  - # of lymph nodes removed (0 vs several)
- With or without reconstruction
  - type of reconstruction
    - expanders vs tissue flap, TRAM vs DIEP, etc.
- Post-op complications
What Can You Expect?

Recovering from mastectomy alone → Many women say their recovery was physically easier than what they expected

Recovering from mastectomy + reconstruction → Additional surgery adds to recovery

What Can You Expect?

Recovery in the hospital

- Longer, more complex surgery = longer hospital stay
  - Mastectomy only: 1-2 days
  - Immediate implant reconstruction: 1-2 days
  - Immediate flap reconstruction: 4-6 days

Varies, depending on the patient and the extent of surgery

What Can You Expect?

Recovery in the hospital

- BP, pulse, respiration closely monitored
- Anesthesia hangover (groggy)
- Nausea medication, if needed
- Surgical bra
- Compression wraps on lower legs
- Sensors to monitor blood flow (flap reconstruction)
**What Can You Expect?**

**Recovery in the hospital**

- Sore throat from intubation
- Sore, numb, pinching or heaviness in chest/underarm
- Self-administered pain pump (you can’t overdose)
- Stay ahead of pain

**What Can You Expect?**

**Recovery in the hospital**

- Deep breathing with spirometer
- Gentle stretching to prevent arm/shoulder stiffness
- Sitting up out of bed, short walks
- Stay hydrated/stool softeners to combat constipation from pain meds

**What Can You Expect?**

**Your overall health affects your recovery**

- Level of fitness: “train for your surgery!”
- Body mass index (BMI)
- Smoking
- Diabetes
- Circulatory issues
- Other health conditions
**What Can You Expect?**

Before surgery, arrange for help during recovery

- Fill prescriptions, including post-op pain meds
- Place needed items where you can easily reach them
- Buy products in smaller, lighter containers
- Arrange for childcare, pet care, carpool, etc.
- Plant to have help around the house
- Freeze easily reheatable meals or recruit friends/family to coordinate meal deliveries
- Helpful hints on FORCE message boards

**What Can You Expect?**

Recovering at home

- Discharged with instructions for incision care, managing drains, identifying signs of infection
- You’ll feel fatigued: Rest. More rest. Repeat.
- Listen to your body. Don’t overdo:
  - No lifting! No laundry! No cleaning!
  - No bouncing or reaching over your head
  - Avoid activities that raise your blood pressure
- Stay ahead of pain: prescribed or OTC painkillers as needed

**What Can You Expect?**

Recovering at home

- Sleep on your unaffected side or on your back* (you’ll be unable to sleep on your stomach or sides after bilateral mastectomy)
- Use a recliner, “nest” of pillows, or foam wedges
- Pillows under forearms
- Practice comfy sleepy positions before your surgery

*gentle back stretches help to avoid backaches
What Can You Expect?
Recovering at home: Bathing/showering
- Sponge baths until doctor okays shower/bath (usually when dressings are removed)
- Use baby wipes
- Use dry shampoo or have someone wash your hair in the sink
- Use handheld shower and/or shower seat

What Can You Expect?
Recovering at home: Dealing with drains
- Surgical drains gather excess blood and fluid
- Sutured at incision site(s)
- Empty/measure/record 2-3 times a day (as needed)
- Keep incision/tubing impeccably clean

What Can You Expect?
Recovering at home: Dealing with drains
- Fluids should steadily decrease, become lighter in color
- Drains usually removed in 7-14 days* when fluid levels are <30 cc (2 tablespoons) in 24 hours
- Advise your doctor if fluid increases, becomes yellow, thick or cloudy; has an unusual or bad odor; or drain tubing comes out

*may be needed longer
What Can You Expect?

Recovering at home: Getting back to driving

- After you no longer need pain medication
- When you have your doctor’s okay
- When you can turn the steering wheel without pain
- Place a rolled up towel or small pillow between chest and seat belt

What Can You Expect?

Help your body heal

- Get adequate rest
- Eat nutritionally balanced meals
- Stay hydrated
- Don’t smoke (quit 6-8 weeks before/after surgery)
- Walk/stretch a bit more each day
- Meditation reduces stress and fatigue

What Can You Expect?

Emotional recovery

- As important as physical recovery
- Give yourself time to deal with:
  - diagnosis, losing breasts, flat chest/new breasts
- Journal or blog
- Focus on the positive
- Meditate
- Talk to others on FORCE message boards, support groups
Potential Post-op Complications

All surgery has potential for risk

• Most women recover from mastectomy without long-lasting or lingering problems
• Sometimes complications do occur
• Know what to look for:
  - pain • redness • fever • wound discharge
• Advise surgeon immediately of any problem

Potential Post-op Complications

Problem: “Frozen shoulder”
Lack of use shortens muscles that support shoulder joints, reducing range-of-motion and mobility

Solution:
- Appropriate exercises while healing
- Gradually increase range of motion
- Physical therapy

Potential Post-op Complications

Problem: Slow wound healing
Chemo • radiation • hematoma/seroma
infection • smoking • circulatory issues
Chronic health conditions

Solution:
- Give your body extra time to heal
- Focus on nutrition to promote healing
- Practice good hygiene to avoid infection
- Revisit surgeon
Potential Post-op Complications

Problem: Cosmetic issues
- Divots, bumps, bulges, flat areas
- Asymmetry or poor positioning
- Too small, too big
- Suture granuloma (immune cells form a mass around internal sutures)

Solution: Revision surgery, liposuction, fat grafting

Potential Post-op Complications

Problem: Poor scar formation
- Hypertrophic (above level of skin)
- Keloids (spread into the skin)
- "Dog ears" (puckers at ends)

Solution:
- Corticosteroid injections
- Laser treatments
- Revision surgery

Potential Post-op Complications

Problem: Hematoma (accumulation of blood in tissue)
- Less likely with electrocautery tools
- Feeling of fullness, discoloration, pain
- Discontinue use of vitamins, aspirin, herbs, blood thinners before and after surgery

Solution:
- If blood isn’t resorbed:
  - Place additional surgical drains
  - Surgical repair of leaking blood vessel (less common)
**Potential Post-op Complications**

**Problem:** Seroma (accumulation of fluid in tissue)  
- Buildup of fluid where tissue has been removed  
- Swelling, sloshing, fullness, redness, discoloration  
- Post-op compression garments decrease likelihood

**Solution:** If fluid isn’t resorbed:  
- Place additional surgical drains  
- Drain with a needle  
- Antibiotics, if infection occurs  
- Surgical repair

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**Potential Post-op Complications**

**Problem:** Infection  
- Despite sterile environment and antibiotics  
- More likely with smokers, health issues, chemo or radiation, expanders/implants

**Solution:** Prevention: Keep wound/surrounding area clean with antibacterial soap; wash hands often  
- Drain fluids  
- Oral or IV antibiotics  
- Remove breast implant, if necessary

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**Potential Post-op Complications**

**Problem:** Necrosis  
- Breast skin is fragile and thin after mastectomy  
- Portion of skin may die if blood supply fails  
- May be hard or discolored  
- More likely: smokers, high BMI, circulatory problems, radiated skin

**Solution:**  
- Wait and see if problem resolves on its own  
- Massage area to soften  
- Debride (surgically remove)
Potential Post-op Complications

Problem: Hypersensitivity
- Caused by irritated nerve endings
- Some sensation returns as nerves regenerate
- May feel burning, tingling, overly sensitive

Solution: Usually subsides in time
- pain medication

Potential Post-op Complications

Problem: Phantom pain
- Similar to loss-of-limb experience
- Itching, pins-and-needles, burning, tingling
- Brain continues to send signals to nerves that are no longer there

Solution: Usually resolves in time
- Pain medication (NSAIDs, prescription opioids)
- Pain management specialist
- Biofeedback

Potential Post-op Complications

Problem: Post Mastectomy Pain Syndrome
- Post-operative pain that doesn’t go away
- Burning pain or dull ache
- Often neuropathic:
  - Sensory nerves in chest severed during mastectomy
  - Sensory nerves in arm may be irritated when lymph nodes are removed
**Potential Post-op Complications**

**Problem:** Post Mastectomy Pain Syndrome

- Often misdiagnosed or unrecognized
- Sometimes assumed to be "normal" post-op pain
- Sometimes ignored
- Often takes extra effort to pursue relief
- More common in younger women, after ALND or post-mastectomy radiation

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**Potential Post-op Complications**

**Problem:** Post Mastectomy Pain Syndrome

**Solution:**
- CT scan for proper diagnosis
- Capsaicin cream, NSAIDs (OTC)
- Corticosteroids, anesthetic patches/injections
- Neuropathic medicines/nerve blocks
- Antidepressants, anticonvulsants
- Physical therapy
- Acupuncture
- Cognitive behavioral techniques (biofeedback, etc.)

Consult with a Pain Management Specialist

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**Lymphedema**

**The Lymph System**

- Works with circulatory and immune systems to promote health and protect the body
- Acts as the body’s drainage and filtering system
- Removes excess fluid from tissues
  - Filters out cellular debris, bacteria, harmful microorganisms
Lymphedema

Blood carries oxygen and nutrients to tissues

90% of blood re-enters the bloodstream. Fluid left behind is "lymph"

Lymph collects cellular waste

Lymph drains into lymph vessels (similar to blood vessels)

Lymph vessels carry lymph to nodes

Hundreds of "knots on a string" filter debris/impurities from lymph

Filtered lymph recycles back into the blood system

Cellular “junk” is expelled through the kidneys and intestines

Image: American Cancer Society

The Lymph System

- Bacteria, viruses, and other pathogens that enter lymph nodes trigger an immune system response

- Disease-fighting white blood cells flood lymph nodes, causing them to swell, i.e., "swollen neck glands" during a cold

- Infection or disease develops when foreign invaders overwhelm this defensive response

Lymphedema

The system’s filtering capability can become impaired when any part of the system is damaged or removed

- Lymph fluid that cannot drain builds up in tissues, causing lymphedema: swelling in the affected area

   like a clogged sink that backs up
**Lymphedema**

- Primary lymphedema is inherited defective or missing lymph nodes or lymph vessels
- Secondary lymphedema occurs when obstructed, damaged or scarred lymph vessels or nodes disrupt lymphatic flow
  - physical trauma (injury)
  - infection
  - obesity
  - immobility

**Lymphedema**

- Cancer treatment is the leading cause in the U.S.
  - removal of lymph nodes to stage cancer
  - radiation therapy, especially to lymph nodes
  - chemotherapy that causes weight gain

Cancer treatment  Lymphedema may develop in:

- head/neck  head/neck
- gynecological  legs, feet, groin, abdomen, vagina
- bladder/colon  legs, feet, abdomen

**Lymphedema**

Breast cancer treatment can cause LE in the arm, hand or shoulder, particularly when axillary nodes are removed or radiated:

More nodes removed = higher risk
- SLNB: 5-17% of women develop LE*
- ALND: 20-53% of women develop LE*

*Source: National Cancer Institute
**Lymphedema**

**Symptoms**
- Visible swelling, asymmetry (or not)
- Aching/tingling/heaviness
- Skin that is red, feels tight or develops textural changes
- Rings, watches, bracelets, sleeves no longer fit well

**Lymphedema**

**Early Stages**
- Skin is soft
- Fluid is mobile
- “Pitting” (indentation remains when skin is pushed)
- Swelling may improve overnight; return during the day
- Easier to manage
- Symptoms can be reversed

**Lymphedema**

Managing early-stage symptoms can prevent lymphedema from progressively becoming worse

Each subsequent phase changes the texture of the surrounding tissue, requiring more attention, more comprehensive treatment, and reducing the likelihood of reversal
**Lymphedema**

**Advanced stages**

- Protein trapped in tissues attracts more fluid; swelling increases
- *Fibrosis* scars and hardens tissue, further blocking lymph drainage
- Overlying skin becomes dry, thick, scaly
- Elevating limb doesn’t resolve or improve swelling
- Cellulitis: fast-spreading skin infection
- Irreversible
- Treatment: reduce fluid volume, soften tissue, reduce risk of infection, maintain/enhance function

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**Lymphedema**

**Precautions: Arm/hand (breast cancer treatment)**

*Use affected arm, but protect it*

- Avoid needlesticks/blood pressure cuffs
- Don’t wear constrictive clothes (tight-fitting sleeves, gloves, bras) or jewelry
- Avoid heavy lifting
- Prevent burns, bites, infection, injury
- Advise health care professionals of your LE risk

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**Lymphedema**

**Precautions: Leg, feet, abdomen (gynecological cancer treatment)**

- Same as breast cancer (precautions applied to affected area)
- Avoid clothing with tight elastic
- Sit without crossing your legs
- Move after sitting or standing for 30 minutes or more
- Stay active to maintain healthy BMI: additional weight increases load on lymph system
Managing Lymphedema

Standard treatment: Complete Decongestive Therapy
- Manual lymph drainage
- Compression
- Exercise
- Skin care

Goal: Manage symptoms and halt progression

Managing Lymphedema

Manual lymph drainage: Specialized massage that manually stimulates/redirects lymph drainage

- Performed by Certified Lymphedema Therapists/other health care professionals with special training
- Gently moves fluid from the affected arm toward abdomen (mimics muscle contraction/breathing)
- Maintenance: By yourself or by a caregiver/partner

Managing Lymphedema

Compression Bandaging

- Reduces swelling and heaviness
- Special stretchy layered bandages (not Ace-style!) over padding
- Worn 23 hours/day until swelling is reduced
- May take several weeks
- Initially done by expert; then bandaging by yourself or caregiver/partner
Managing Lymphedema

Compression Bandaging

- Compression garments
  - Used after bandaging reduces swelling
  - Sleeves/gloves for arms/hands; stockings for legs
  - Initially fitted by expert
  - Different sizes/levels of compression
  - Compression garments worn during the day, nighttime bandaging as required

Compression sleeves

*Important that they are medically sound and perform as needed
Managing Lymphedema

Exercise

- Stimulates lymphatic function
- Use a CLT-guided program
- Stretching ~ aerobic activity ~ the right type of strength training ~ flexibility
- Perform while wearing appropriate compression garment

Managing Lymphedema

Skin care is critically important!

- High level of protein in stagnated lymph encourages infection, particularly cellulitis
- Diligent hygiene of affected area helps to prevent germs/ infection and moisturizes fragile dry skin
- Repeated treatment for infections can lead to antibiotic resistance

Managing Lymphedema

Surgical approaches

- Relatively recent in U.S.
- Lymphatic bypass and lymph node transfer require microsurgical skills
- Few qualified surgeons
- Most U.S. studies have been self-reporting by surgeons; no clinical trials
- Insurance may not cover
Managing Lymphedema

Three new surgical approaches

Not a cure or primary approach to treatment, lymphedema surgery can:

- reduce the time needed to manage affected area
- improve aesthetic appearance
- improve overall quality of life

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Managing Lymphedema

Surgical approaches

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<td>Reduce volume/weight from chronic LE</td>
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<td>Improves lymphatic function</td>
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<td>Vascularized lymph node transfer</td>
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Managing Lymphedema

Surgical approaches: Debulking

- Addresses chronic LE, when fluid continues to accumulate; fat and protein deposit in the soft tissues, adding significant volume and weight

- Excisional surgery or suction-assisted protein lumpectomy (liposuction) reduces overall size of limb

- Especially helpful for greatly oversized limbs
Managing Lymphedema

Debulking: Liposuction

Managing Lymphedema

Lymphatic Bypass

Creates a new lymphatic pathway by connecting blocked lymph vessels to healthy blood or lymph vessels

- Best for early-stage lymphedema (swelling is primarily fluid)
- Requires microsurgical skills to connect vessels that are finer than human hair

Image: David Chang, MD
Managing Lymphedema

Lymph node transfer

- Best for early-stage lymphedema (swelling is primarily fluid)
- Replaces damaged or missing nodes with patient’s healthy nodes to restore effective lymphatic drainage
- Healthy nodes moved to lymphatic area; groin nodes are most often removed during DIEP breast reconstruction

Managing Lymphedema

Requires continuation of risk reduction practices, MLD and compression garments to protect against recurrent swelling

Images: Fox Chase Cancer Center

Managing Lymphedema

Lymph node transfer

Images: Jay Granzow, MD
Managing Lymphedema

LE cannot be cured, but it can be managed

Prevention = lifelong precautions

Early diagnosis = essential

Treatment = lifelong diligence/management