

DCIS

Ductal Carcinoma In Situ

SCIENCE & EXPERIENCE

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in consultation with
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If you are reading this booklet, you or someone you know has probably been diagnosed with DCIS. In my 10 years of working with patients with DCIS and breast cancer, I have often found that the diagnosis of DCIS is even more difficult to come to terms with than invasive breast cancer, and that treatment decisions are also more challenging to make.

As I have helped women grapple with understanding the disease and its implications, I have felt that we have more questions than answers about how best to treat this problem. This is despite an excellent outcome from those treated with DCIS — fewer than 1% of patients with DCIS will die of breast cancer. However, this outcome is achieved at some cost. Surgery and radiation are not without side effects. And for many women, facing DCIS is their first encounter with not only the medical field but the uncertainty of life.

I thank Elizabeth for the courage to share her very personal story with us. Although each individual's story is unique, I am sure you will find that many of her feelings and experiences are universal. Because she wrote of her experiences as they unfolded, the telling has a very special immediacy which you may identify with. The medical information in this booklet is useful but by no means exhaustive and you will certainly have additional questions you will want to discuss with your health provider. The references provided are also excellent sources for further research on DCIS.

You will no doubt be changed by your experience. However I hope that you, like Elizabeth, will be able to move forward in your life and the world, finding yourself stronger for having faced this challenge. I wish you wisdom and grace in your journey.

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A DCIS (Ductal Carcinoma In Situ) diagnosis is a shocker. That may be the only similarity between my experience and anyone else's.

My DCIS diagnosis came in the spring of 2004. I wrote to focus on what was happening in and to my body, and what it meant to me. I had questions and sought answers. When treatment ended, friends encouraged me to share my journey more widely.

I am now a sixty-seven year old woman, a Catholic nun early on and now happily married to Tom Hall. I have spent my career working to prevent injury and violence, straddling the gap between academia and the general public. From both professional and personal perspectives, I know the power of survivor activism and story-telling.

I hope this booklet has power. If I hear that it was informative, or encouraged sharing, or made someone feel less isolated for feeling as she does, I am happy.

So here it is.

Elizabeth McLoughlin, ScD

San Francisco, CA
September, 2008

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❖ What is Ductal Carcinoma In Situ?

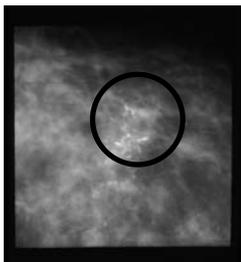
“Ductal” means “of the duct.” The breast is a bundle of milk glands encased in fatty tissue. The glands secrete milk during the breast-feeding of an infant. Ducts are the channels which bring the milk from the gland to the nipple.

“Carcinoma” means a collection of cancer cells.

“In situ” is a Latin term meaning “in place,” usually in the place of origin. For “ductal carcinoma in situ,” the diagnosis indicates that the cancer cells remain inside the duct and have not spread to the surrounding fatty (breast) tissue.

DCIS can be detected by a routine mammogram. A mammogram is an x-ray picture of the breast’s glands, ducts, and fatty tissue. A woman stands against a mammogram machine and a technician flattens the breast between 2 plates. A beam of radiation (usually a 0.1 to 0.2 rad dose per picture, or about a tenth of radiation exposure during a flight across the United States) is sent through the breast tissue onto a sensitized surface. The resulting picture can be on film, or digitized for computer access. If there are specific areas of concern, the technician can use various magnifiers to provide enlarged images of the area of the lump or calcification.

When routine mammograms reveal calcifications (specks of calcium) that appear suspicious to the radiologist, further tests determine if these calcifications contain DCIS. Currently DCIS accounts for nearly twenty percent of all “breast cancers” detected by screening in the United States. About 60,000 new cases are diagnosed each year.



Abnormal mammogram with calcifications

I am analyzing suicides among San Francisco residents, questioning exactly how many people jump from the Golden Gate Bridge. I’m preparing a *Profile of Injury in San Francisco* for the SF Injury Center.

The phone rings. It’s my nurse practitioner. My attention jerks from bridge jumpers to the voice in my ear.

“They found DCIS in your breast.”

Silence at both ends of the line. She could have been speaking Swahili.

“What?” I ask, heartbeat a little fast, breath a little shallow.

“DCIS. Ductal carcinoma in situ,” she says.

“What did you say?” I reply. “I’m having trouble hearing you.”

“Sorry. It’s DCIS, a kind of breast cancer. But if you have to have breast cancer, it’s the best kind to have. You should be fine after it is treated.”

I’m suspended inside the unleapable gap between what I am hearing and what I understand. But the pragmatist self elbows out the stunned one.

“What do I do now?” I ask, mostly to myself, but also into the receiver. Judy outlines my options, suggests giving myself time to take this in, and says how sorry she is. We hang up.

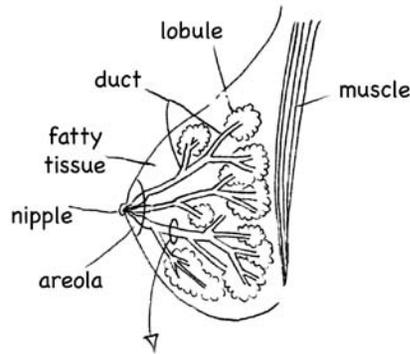
My husband is in Thailand, giving a workshop on health workforce issues. Everyone else in my family is at least 3,000 miles away. I have loads of friends nearby, but right now, I’m sitting alone with a cancer diagnosis.

“This is unbelievable,” I think to myself. Through my window, I watch a container ship slowly head out into the open ocean. My mind jabs at the news like a boxer trying to find a vulnerability in her opponent, but I hit nothing. A red-tailed hawk soars at eye level, wings making minute adjustments, wing-tip feathers flared. *Breast cancer*. The leaves on the trees below the window respond gently to an unseen breeze. *Cancer*. A small bronze Indian goddess sits in the lotus position on my windowsill, uplifted hands delicate. *Breast cancer*. Clouds, grey underbellies topped with mounds of multi-shaded white, scrape the towers of Golden Gate Bridge. *Cancer*. Unbelievable.

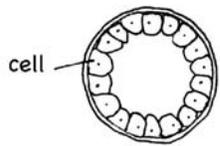


Is DCIS Cancer?

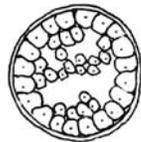
The literature is inconsistent about the answer to this question. Cancer cells are present, but they are within the milk ducts of the breast and have not spread from their tissue of origin. Some experts call it “pre-cancerous,” that is, not yet cancer, because the cancer cells are contained within the duct. Others say cancer is cancer, and cancer cells, whatever they are doing, should be called cancer. Given the dread attached to the word “cancer,” many women choose to call the condition by its name: DCIS or ductal carcinoma in situ.



CROSS-SECTION VIEW OF DUCT

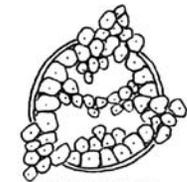


NORMAL



DCIS

Treating DCIS will reduce the risk of progression to...



INVASIVE CANCER (outside the duct)

CANCER CELLS IN OTHER PARTS OF BODY

METASTATIC CANCER

“Do I have cancer or don’t I?” Sounds simple, but it’s not. It is huge. “Cancer” conjures up horrible tests and treatments, surgeries, mutilation, pain, and death. “Not cancer” means life as usual.

After my diagnosis, I am suspended between these two possibilities, almost as if I have to choose. They tell me I have cancer cells in my body, and I slide into a “poor me” cancer patient role. Then I whip around 180° and think, this surgery and radiation treatment is overkill for a condition that no one knew about until mammography became routine. Its natural progression is not known and experts cannot agree about what it is.

When I was very young and sometimes feeling unappreciated, a middle child in a large Irish Catholic family, I’d lie at night imagining myself terribly sick in a hospital bed, tubes coming out of everywhere. My parents would hover nearby and tell me they loved me. I would be still, soaking in their undivided attention. It was all imaginary, yet very comforting, and I would fall asleep.

That was long ago. Now, sleep comes, but I still have DCIS when I wake up. I try to force a psychic lid on my dilemma, stiff-arming my doubts into tiny crevices inside me. But as soon as I stop shoving them down, they pop right back up again. I try another tactic— stare it straight in the eye. I have cancer cells in my breast, and a surgeon will cut them out. That quiets my mind, until I start to think — then what? So I try the old self-bossing: Press the “off” button! I have what I have, I’ll do what I have to do. Squeeze my eyes, clench my fists, breathe deeply, and come what may.

Nothing seems to work.



Is DCIS life threatening?

There have been no scientific studies to follow the natural course of DCIS without treatment, because most patients choose some form of treatment upon diagnosis. If properly treated, the odds that a woman will die of the original DCIS are very small. If DCIS is left untreated, it has the potential to spread outside the milk ducts and become invasive cancer. However, not all DCIS becomes invasive cancer. Because the outcome of untreated DCIS over time is unknown, we do not know which DCIS will become invasive cancer and how long it takes to become invasive cancer. Having had DCIS means that you are more likely than other women to have DCIS recur in the remaining breast tissue, or to get breast cancer in the other breast. It is important to remember that the current goal for DCIS treatment is prevention of future breast cancer.

I've known for about an hour that I have DCIS. I stare out the window, the sky grey with the remnants of rain clouds.

"Am I going to die?" That question comes up relentlessly, despite my efforts to banish it. What a brutal, stupid question! Of course I am going to die.

But I don't want to die of this. I am appalled that I might be growing a killer inside me. Experts say DCIS won't kill me, but I hear "cancer" and foreboding seeps in.

When I was nineteen, my eighteen-year-old sister was hit by a car, and died in three hours. I was off traveling, and my mother called me. Death was announced by a phone call — unexpected, irreversible, world-shattering. But as excruciating as her sudden death was, I survived it.

This is different. For me to start a slow downward slide into inevitable pain, suffering and a prolonged death watch — no, no, no, no, no!

I don't want to know the particulars of the rest of my life — when I will die and of what. I want to live as if life will last forever.

I need inner or outer space to sort out what I have just heard. I stare out the window. At that moment, a double rainbow emerges and arcs across the northeast sky. One is bright and distinct, the other a whisper of its adjacent colors.

"A rainbow!" It is the Biblical symbol of God's steadfast protection. I know rainbows come from sunbeams hitting moisture at just the right angle, I know that!

But it comforts me.

❖ What happens after an abnormal mammogram?

When a breast abnormality is discovered on a screening mammogram, there are additional diagnostic imaging tools and biopsy tests to explore these findings.

A common test for DCIS is the core needle biopsy, which withdraws tissue from the breast. A pathologist examines this tissue to search for cancer cells and reports findings to the patient's healthcare provider who then informs the patient.

If a breast lump can be felt, a fine needle aspiration is used to draw fluid or tissue from the cyst or tumor, and this is examined by a pathologist to determine if cancer cells are present.

An ultrasound is an imaging technique that uses high frequency sound waves to create pictures of the breast. It can be used to find tumors in women with dense breast tissue or in women with breast implants. It is usually used together with a mammogram.

When a doctor needs information in addition to the mammogram or ultrasound, a breast Magnetic Resonance Imaging (MRI) is occasionally used as part of work-up for DCIS. It is important to keep in mind that an MRI is an additional tool and should not replace standard tests and exams (mammogram, clinical and self-exams).

Pre-diagnosis: I've had two abnormal mammograms. Next week they will do a core needle biopsy. Who should know what is happening to me?

My mother poses the real dilemma. She is a vivacious widow, ninety-six years of age and ninety-six pounds of person, living alone with her dachshund Pushkin on the other coast. An avid bridge player, she plays cards and life with a full deck. We don't see each other often, so we depend on self-report. We've promised to be honest with each other. I want her to tell me about her health, but I'm reluctant to talk about mine.

Why worry her now? I call my older sister. In the end, I decide to tell her. I factor in the time zones for when Mother is at full strength and dial her number.

"Hello?" Mother says tentatively, ever curious who might want to talk to her.

"Well, hi there," I say. We always start our calls the same way and chat about what each is doing.

Then I take a deep breath. "There is one other thing. I'm only telling you because we promised that we would." I pause but she says nothing.

"I'm having a core needle biopsy next week, because they saw something in a mammogram they didn't like."

A long pause: "What does that mean?" My question exactly.

"Well, it's just a test, maybe it's nothing. Hope so."

"Did you feel a lump?"

"No. But I have lumpy breasts. You remember when I've had lumps aspirated. Each time it was nothing."

"Well" ...long pause..." maybe we shouldn't worry until we know for sure," she says.

"I'll call you as soon as they tell me anything, I promise. And I love you."

"I love you, my sunshine," she says, and the line goes dead.

I let out a deep breath. She'll worry — that's for sure. But she worries about us all the time anyway. She can just tuck me yet more firmly into her prayers. That won't be all bad.

❖ What is a stereotactic core needle biopsy?

A core needle biopsy is a procedure which removes several tissue samples from the breast using a hollow bore needle. "Stereotactic" is a method of showing a 3-dimensional view of the breast while the core specimens are taken. Two mammographic imaging plates are positioned on either side of the breast, and show via a computer screen exactly where the calcifications are located. Thus doctors can place the needle through this tissue and come away with a useful core tissue specimen. Each specimen is immediately examined to determine if it contains calcifications. The specimens are then sent to a pathologist who determines if cancer cells are found in the tissue.

I enter the treatment room in the radiology suite. "Okay, you can slide your gown off your shoulders, and lie down face-down on this table." The table has a hole in it. "Just drop your left breast through that hole," the technician advises. I do as I am told.

"Comfortable?" she asks as she presses a foot pedal to elevate the table, just like they do to cars on racks at service stations. A man and woman go underneath me and sit down.

"You have to lie perfectly still for the next forty-five minutes," says the man.

I am not going far because they have just squeezed my left breast in a vise grip. Whispered talk accompanies loud machine sounds. I can see nothing, but feel them scrub my breast and stick it with a needle.

"You'll hear a loud clicking," the man says, "and then you will feel a slight jab."

Okay, forewarned is forearmed and I am ready. No problem. Then, without warning, pain explodes near my nipple. A spasm vibrates through me, but I cannot get away.

"Did you feel that?" asks the voice.

"Well, yes," I answer, still shaking, "I guess I wasn't expecting anything that intense."

There are mumblings from below about adding more pain meds. I guess they do, but my jaw still clenches. My whole body awaits another blow. I tell myself it's survival mode now. Turn off as many sense receptors as possible and hold on 'til it's over.

A few more times I hear a click and feel a muted punch, and then it is over. All I want to do is get out of here. I sit up unsteadily, then leave with a sore left breast, steri-strips, an ice pack, and a big ugly bruise forming.

I leave behind a tiny part of my breast and also my conviction that I am in charge.



What support is available for women with DCIS?

Women respond to the crisis of the new diagnosis of DCIS in many different ways. It is often helpful to ponder the question “what has helped me before when facing an emotionally hard time?” Support groups, individual counseling or therapy, and peer counseling are useful resources for people trying to cope with difficult situations. In group settings, people come together who have experienced a similar crisis. Many breast centers offer professionally-led groups for women undergoing cancer treatment. Groups can pierce the isolation so commonly felt by someone in crisis, the sense that “no one feels the way I do.” People share problems and practical solutions that they themselves find helpful. While groups are not for everyone, even skeptics who attend regularly may find comfort there. Others may choose a single survivor to guide their journey. For others, an emotional or spiritual crisis may be sparked by this new diagnosis for which the healing strategy is individual counseling or therapy. Women turn to friends, family, clergy, pre-existing support groups, the creative arts and all that comforts them. It is wise not to try to endure the diagnosis and treatment alone. What appears to provide the most useful support is that which decreases isolation, and helps a woman feel heard, understood and supported.

I cannot sit and do nothing, knowing I have DCIS.

I’m second born. My whole life, I’ve watched someone try something before I do. Then I figure out how to make it work for me. Who can be my older sister in this plunge into the unknown?

I think... Louise. Louise is a breast cancer survivor, somewhat older than I, a commanding presence with impeccable connections and a fierce commitment to cancer patients’ rights. I don’t know her well, but we’ve been to each other’s homes. I respect her enormously, and I need her. I pick up the phone.

“Louise, they just told me I have breast cancer, and I don’t know what to do,” I blurt out.

“Oh, dear. I’m really sorry. Really. But tell me now, what exactly did they tell you?”

I tell what I remember. She questions and I answer. Sharing with someone who can help feels useful. Louise tells me who to call for an appointment, what test results to bring, reassures me that what is happening is serious yet manageable. I promise to follow up on her advice, and hang up.

Forty-five minutes later, the doorbell rings. It’s Louise, bringing a book for women newly diagnosed with breast cancer.

“I just went to the book store and found this. I think it might have some good info.” She gives me a hug. “Call if there is anything I can do for you. Promise?” I promise. I give her a squeeze and she leaves.

Louise accompanies me every step of the way. I watch her waver between telling me what I ‘should do,’ and respecting my independent streak, wanting options, not ‘thou shalt.’ Actually, it is very confusing. I want both.

But Louise gives me more than advice. I learn more deeply what it is to be loved and cared for by friends. It goes both ways. When I am needy, friends delight in being needed. New for me, a slow learner. But Louise and Tom are gentle teachers.

❖ What is the preparation for surgery?

There is no one right way to prepare for an ordeal, be it surgery, a test or performance, or a painful emotional event. Each woman develops coping strategies to get herself through the days leading up to the surgery. Some choose solitude; some depend on a partner or single trusted friend; others surround themselves with lots of loving friends.

Since a lumpectomy is usually an out-patient procedure which does not require hospital admission, most women seek a family member or close friend to provide comfort and transport to and from surgery. When a woman undergoes a mastectomy, she will stay in the hospital for at least one day after the surgery. The length of hospital stay after a mastectomy also depends on whether the woman has reconstructive surgery and the type of reconstructive surgery.

Usually a woman undergoing breast surgery will have a preoperative appointment to make sure that she knows what to expect from surgery as well as exams and tests to ensure that there are no underlying medical problems. Specific information from your doctor or nurse and schedulers should be given to you to tell you about what to do before surgery about eating, drinking, pre-surgery appointments, testing and medications.

It is useful to think about the time before surgery as a time to practice the very best self-care strategies: good, healthy nutrition, moderate exercise that feels good to do, stress-reduction activities (don't forget distraction, humor and fun). Some women find that a ritual with family or friends or a healing practice can be helpful.

It's the day before surgery. I'm about to lose a part of me, and I want a picture to remember it by.

We go down to the living room for its natural light. I hand Tom the camera. Outside, tree limbs and leaves bend, stretch and shudder as rain and wind envelope them. I start unbuttoning my blouse. Tom reaches up inside it to unhook my bra. I stand, naked to the waist.

"Do you want your face in it?" he asks.

"At least for one picture", I reply. I take off my glasses and smile.

"Nothing's happening," Tom says. Tom has never mastered my digital camera. He hands it to me. "Does this have a close-up?" he asks.

I show him the toggle switch and step back.

Tom aims the camera at me and pushes the button. It works. He shows me the viewing screen.

"How's that?" he asks.

I stare at the screen. There I am, a middle-aged woman with middle-aged breasts. The image doesn't match how I feel.

"Um," I grimace. "Here, give me the camera for a sec." I rotate the lens so that both the screen and the lens face me. I line up just my two breasts in the frame and push the button.

"Look, they don't seem to match each other," I muse, looking at the image of breasts which fill the tiny screen.

"Let's see." Tom scrutinizes the image. "You're right," he says, "they aren't even. Go look at yourself in the mirror."

I go into the bathroom, turn on the light. I stare at my breasts as if I had never seen them before. They really aren't symmetrical. They seem alien, not a part of me.

Why am I so worried about reshaping one of them if they don't match anyway. I don't know. But it *does* matter — a lot.



What is wire localization?

Most DCIS cannot be felt on examination and the calcifications cannot be seen by a surgeon. For women undergoing lumpectomy, to ensure that the correct area is removed at surgery, this area must be marked for the surgeon. This procedure is called wire localization. On the day of surgery, the radiologist inserts a thin wire or wires into the breast to guide the surgeon to the tissue to be removed. Using local anesthesia to numb the breast and guided by mammography or ultrasound, a radiologist inserts hollow needles into the breast through which the wires will be placed. When the needles are withdrawn, the hooked wires remain in place inside the breast. The loose ends are taped securely to the breast, and the woman goes to surgery. Wire localization is not required for women undergoing mastectomy.

It is surgery day. I'm in a mammography room, determinedly out of touch with my body. The nurse flattens my left breast, aligns it, x-rays it, then leaves the room. All alone, I hug the support beam of the machine which immobilizes my breast. More colorfully clad, I could be a butterfly pinned in a display case.

The doctor enters. She is friendly with dual airs of competence and compassion. Explaining everything, she scrubs my breast, then shoots in a light anesthetic. Her two long needles slide in painlessly. X-rays confirm proper placement. Then she crouches down under the machine, and gingerly maneuvers the breast with its protruding needles out from the machine.

It's early spring, Oscar awards season. I wonder what kind of movie would include this scene. Horror film: "Cockroach invades breast; two wiry antennae probe surrounding air!" Med-tech documentary: "Women want to salvage breasts; new techniques permit it." Comedy: "With all this focus on tits, what's up with the ass?"

The doctor injects dye and inserts a hooked wire through one of the needles into the breast. "You may feel a slight tug." I'm passive, not feeling much on purpose. She repeats the procedure for the second wire, then removes both needles. "That's all." She smiles at me. "Now we just have to tape these wires down so you don't have to worry about them."

She covers the wires with lots of tape. My breast almost disappears. I feel light-headed, spinning toward darkness. I say I'm feeling woozy. She releases the chair's back and I lie flat.

"It's probably that you hold yourself together tight for the procedure, and then you let go — really let go!" the doctor suggests.

She's right. I lie there until I feel steady enough to sit upright. "One down, but lots more yet to come today."

The nurse helps me slide off the chair. I pull the hospital gown around me, gather up my belongings and, as numb as my left breast, trudge up the staircase to the surgical floor.



What is a lumpectomy?

A lumpectomy is surgery that removes only the breast tissue containing cancer cells, sparing the healthy breast tissue. The name can confuse DCIS patients who rarely have a “lump” or tumor. It is also called breast-conserving surgery or a partial mastectomy. The location, extent and depth of the incision and the amount of tissue removed depends upon the DCIS. Since most DCIS cannot be seen or felt, the patient’s mammograms and “wire localization” are important guides for the surgeon.

After wire localization is performed, the patient comes to the operating room for the surgical procedure. Lumpectomy is commonly performed with either local or general anesthesia, with the choice of anesthesia dependent on patient preference and extent of the planned surgery. Generally, the surgery lasts for about one hour. The surgeon numbs the breast, and removes the tissue marked by the localizing wires, with the wires removed as part of the specimen. The specimen is then examined with an x-ray to confirm that the microcalcifications have been removed with the breast tissue. Tiny surgical clips much like the ones often inserted at core biopsy are often placed at the lumpectomy site to mark the area for future mammograms.

The breast incision is then closed, dressings are placed on the incision, and the patient is taken to the recovery room to recover from anesthesia before going home. In general, the pain and discomfort from a lumpectomy are easily controlled with oral pain medications, which are rarely required for longer than a week. Patients often return to regular activity within a few days, although this timetable may vary depending on how much tissue was removed.

Both the surgery itself as well as the recovery process differ significantly for women undergoing mastectomy. For additional information regarding mastectomy and reconstruction, please refer to: www.ucsfbreastcarecenter.org/guideindex.html

The tissue removed at surgery is sent to the pathologist for analysis, where the size and characteristics of DCIS as well as the margins are assessed. The process of pathologic evaluation takes about a week. The results of the pathology review are discussed at the first postoperative appointment.

I’ve climbed up the stairs from mammography and now I’m on top of the high hospital bed in my non-skid hospital booties. I’m like a kid prepared for a long journey and I’ve brought along my toys. I dig into my cross-stitch bag for my eagle tapestry, needle and threads, then stick in my iPod earphones. I am transported to the land of *Angels and Demons*.

Louise, my friend and guide, appears, needlepoint bag over her arm, and soon she and I are stitching together, with not a lot to say, even though I turned off the iPod.

Tom arrives, smiles apprehensively and sits down. Louise works her needlepoint.

In walks a man with green scrubs, a friendly smile and a mask pulled down around his neck. Louise rises, puts away her needlework, bids the others goodbye and gives me a hug.

“I’m your anesthesiologist,” the green-clad visitor says. “Are you the one who biked across the country?”

“I am,” I say. That ride feels like it happened in another transmigration of soul.

“Then this ought to be nothing,” he says.

“Right,” I say to myself.

“Throw your head way back,” he says, and I do.

“Great extension,” he says with a grin. “No worries,” and with that assurance, out he goes.

In comes my surgeon, also in scrubs. “Hi, this is it,” she says, and signs her initials on my left shoulder. I watch as she moves the felt tip pen on my skin. A simple act, but I’m the writing surface. Soon she’ll wield a scalpel, not a pen. It’s better not to think about all this.

Two orderlies arrive with a rolling gurney. I climb on board, hair tucked into a green cap. Tom, I and the entourage head for the OR. Tom kisses me in front of the swinging doors, and we leave each other for opposite directions.

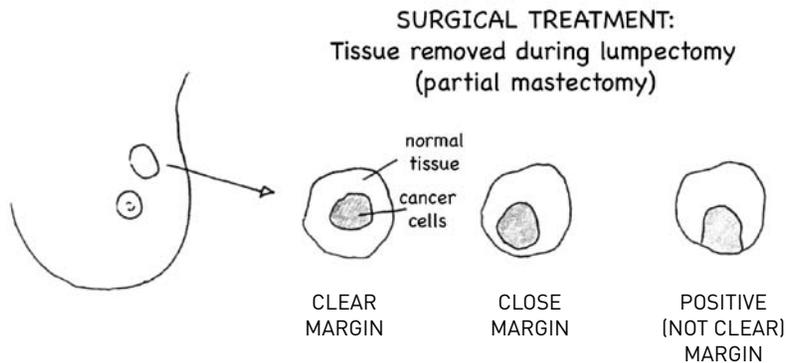
I’m parked inside some OR space for who knows how long, watching staff bustle about. Finally, someone comes over, puts a mask over my mouth, and says “take a deep breath.”

And I go to sleep and have no clue what happens in the OR.



What are clear margins?

“Clear margins” signal the completion of surgery to remove cancer. It means that the surgeon has removed all the DCIS-involved tissue, and the pathologist finds no cancer cells in the surrounding tissue, called a margin. Although it is normal to want to know how wide the margin should be, there is no “one size fits all.” There are many factors to consider, including the location of DCIS in the breast, the surgeon’s judgment during the operation, and the physical changes which occur when the tissue is prepared for the pathologist’s analysis. If cancer cells remain at or close to the margin (true in about twenty-five percent of cases), the surgeon will re-operate, remove more tissue through the same scar and send this tissue to the pathologist. This is called a re-excision. This is repeated until “clear margins” are confirmed, although more than two surgeries is uncommon.



Waiting for a pathology report is like waiting for a jury verdict. I am living in a two-tiered space. Life is normal on the main floor, but some suspicious things lurk in the basement like sounds, smells, and creakings that bode ill. It’s the basement that harbors the dread. I go there in my dreams. I had one last night — sketchy but forceful. I’m watching my surgeon (although she was a movie producer in the dream) for clues about the path report and something about her manner points to bad news.

I’m a primitive woman, reading the future not in tea leaves or chicken entrails, but in dreams. The ten days pass slowly.

Tom and I go to my follow-up visit with my surgeon, expecting to get the pathology report. But no report. My surgeon goes to the lab, looks at the slides, and reports back that although all looks good, she isn’t a pathologist, so we must wait for the report. Come evening, she calls and tells me that the pathologist had signed off on a “no more surgery” report, so I’m good to go.

Deep down, I feel like I’ve taken advantage of my family and friends, alarming them unnecessarily. It’s just DCIS, not breast cancer. They take out a little tissue, say they have it all, do a little radiation, and that’s that. I’ve generated all this concern and care and prayers, and it was nothing.

But relief overwhelms and buries self-scoldings. “I’m clean!” I shout to everyone within earshot or phone distance. Everyone I tell is thrilled and relieved.

My surgeon calls back two days later. “Liz,” she says, “the pathologist found a dirty margin.”

“What? Why? You said the margins were clean.”

“I did. But now I am reading the report.”

“How come it is different? And why can’t radiation take care of left-over debris?”

“The clinic’s radiologists won’t start until pathology makes a final report of clean margins, and pathology won’t do that.”

“So now what?” I ask, a bit shell-shocked. I’ve lived liberated for forty-eight hours, now get plunged back into the reality of another anesthesia, another recovery, tape to pull off the tender spots, telling Tom and Mother and all my friends...

❖ What follow-up is required after a lumpectomy?

After surgery, physicians use mammograms to make sure that all the calcifications were removed during the lumpectomy. This is generally done before starting radiation therapy and also serves as a new baseline. Part of the long-term follow-up after a lumpectomy for DCIS involves a mammogram of the involved breast every 6–12 months, and an annual mammogram of the other breast.

A resident prepping me for radiation asks if I had a mammogram after my last surgery. I say no. He says I need one. The radiologists are adamant: no radiation until no DCIS — with x-ray proof.

So here I am, bare-breasted, standing in front of the mammogram machine which has the power of a hanging judge: This breast can stay; this one must go. The technician readies me and the machine, then she slips behind a glass enclosure. “Don’t breathe...don’t breathe...don’t breathe.” The machine whirs and stops. “Okay, breathe.” She disappears with the plates. I am distracted, uneasy.

The door opens. “Now we’ll do some magnifications,” the technician says. One exposure later, she leaves to check her technique. I reassure myself. “Stupid to shoot me full of radiation if the films aren’t useful.” Back to waiting, my magazine is now furled like a club. What if they are seeing micro-calcifications? What if I need a mastectomy?

Next she announces that she will use magnification from three different angles. I search her face and body language for clues, but she is impassive. More squeezing, more not breathing, and she disappears again.

I’m losing the battle against dread. I had thought radiation was just mop-up after a messy spill. But maybe not for me. She selects a rectangular magnifying paddle from the rack. “I’m getting kind of scared,” I blurt out. “Are they seeing something they don’t like?” She brings the paddle over to the machine and inserts it into its slot. “I know this is very hard on patients,” she replies. “But we’re trying to make sure we see everything we should.”

“Reading tea leaves,” I say to her, “body language and facial expressions — that’s all I have.” I approach the machine. My breast is squeezed and I don’t breathe. She leaves. I wait, fighting to turn off my brain.

She returns with a smile. “The doctor looked at the films and everything looks fine,” she says. I feel relief of sorts, but do I trust her? Maybe...maybe not.



Is a lumpectomy disfiguring?

The term “disfigurement” usually means that something has happened to a part of the body that makes it look different from the norm and less attractive. Breasts come in all shapes and sizes and are usually not symmetrical. Normal usually means a nipple, an areola surrounding it, and smooth, intact skin surfaces. A lumpectomy removes part of the breast, and leaves a scar and a breast shape determined by the location and extent of the surgery. Whether a woman experiences her changes as “disfigurement” depends upon how she and others who see and touch her body think and feel about her breasts. It is not unusual to have questions and concerns about these changes. The surgeon or nurse can answer questions about expectations of the changes. If needed, support professionals can help with adaptation to and coping with body changes. However, it is important to remember that the goal of lumpectomy is to preserve the breast, including shape and symmetry.

At exactly forty-eight hours post-op, I unhook the surgical bra, strip off the tape and remove fistfuls of cotton packing from my left breast. I stare into the mirror. Sure, tape covers the excision which is surrounded by huge bruises, but I don't care. Most of my breast is still there.

Will everyone be looking at the left side of my shirt to see if they notice anything different? And do I mind?

I worked in a pediatric burn unit for eight years, so I know about disfigurement. At first, I saw scars instead of kids. The kids coming back to the unit for reconstructive surgery had huge, bad scars. But the longer I worked with these kids, the more their scars, even major facial scars, seemed beside the point, rips in the outer packaging. Not for the kid probably, but for me. Each kid was different and I liked some better than others. After a while, I don't think I saw the scars all that much.

I once dreamt that I was badly burned and massively scarred. I woke up feeling somehow initiated into a secret society.

In some cultures, the rite of initiation includes slashing to create facial scars. Scars mean experience, survival. In some odd way, I feel the same way with the scar on my breast. Without being asked and having no choice, I have been initiated into a new and very large group of women who are dealing with DCIS. My proof of belonging is my scar.



What is radiation therapy?

Radiation therapy uses high-energy beams to kill cancer cells. Radiation kills cancer cells by causing the production of “free radicals.” This process changes the DNA of the cancer cells and prevents them from reproducing. The cancer cells die when they can no longer multiply and the body naturally eliminates them. Healthy tissues are spared the effects of radiation because they, unlike cancer cells, can repair the DNA changes. In addition, normal tissues are shielded as much as possible while targeting the radiation to the cancer site. Radiation therapy in DCIS is primarily recommended after surgery to reduce the risk of local recurrence. However, the decision about whether to have radiation for DCIS is an individual one, made on the basis of many factors including choice of surgery, patient age, characteristics of DCIS, and patient preference.

A linear accelerator is programmed to deliver the appropriate dose to precise locations, with all other areas properly shielded. With vital organs located directly underneath the breast and rib cage, rays are aimed at the breast from each side, rather than from the front. All this is designed and programmed for each individual patient during a preparation session called simulation.

The specific number of treatments is determined by your radiation oncologist and based on the characteristics of the DCIS, its location and what other treatments are planned. Most people are treated 5 days a week, Monday through Friday, for 5 to 6 weeks. The weekend rest permits the recovery of normal cells between radiation treatments.

Technical information: The standard dose for the whole breast is usually 44 to 50 gray (Gy), delivered in fractions of 180 to 200 centigray (cGy), followed by a boost to the surgical cavity using electrons in 200cGy fractions up to 66Gy. 1 cGy equals one rad (“radiation absorbed dose”); 1 Gy = 100 rad. For perspective, a single whole body exposure of more than 7 Gy is usually fatal; the current mammography machine uses about 0.1 to 0.2 rad dose per picture.

It’s time to ready the machinery to radiate me. I lie bare-breasted in semi-darkness in the inner sanctum of radiation oncology. Fine green lines crisscross my body, beamed from above and aside. Two crutch-rests pull my left arm back and away from my body. A male tech points a digital camera at me, snaps a few close-ups of my breast, then reaches for a Polaroid and takes some more.

Out of body, I watch. Men and women take turns drawing lines and crosses on my breast and chest with permanent ink felt pens. There are coordinates flashing on the monitor, body-markings, commands of “don’t move,” people departing.

While they are away, safe from the powerful rays, the machine clicks and whirrs, rotates above me and then clicks and whirrs some more. It mimics a praying mantis gesturing over a stunned fly before devouring it.

The white coats return. A male tech leans over me and draws four crosses: one midway between my breasts, one near the nipple, one right on my incision scar and one down my rib cage.

“Can you do the tattoos?” he asks the female tech, “I left my glasses somewhere.”

“Oh great,” I think, “all this fine-tuning by a blind man.”

The young woman pricks her needle into the four crosses on my chest and breast. She smiles and talks to me.

“Now just a few more pictures, and we’re finished.” She aims her camera at my tattooed breast, and it clicks.

The machines pull away, the gurney moves slowly back to its original position, and I sit up. “One more picture, this time your face. It’ll go on your treatment screen, just to assure us that it’s you.”

I smile into the camera, and the flash splats light at me.

I go back to the changing room, take off the hospital gown, put on my street clothes and walk away. In my tradition, it’s Holy Thursday. Tomorrow is Good Friday, then Holy Saturday, then Easter Sunday. Passion, death and resurrection.

❖ Does exercise help patients cope with DCIS treatment?

Aerobic exercise helps to control weight, improve cardiovascular fitness, lower blood pressure, and reduce stress for people in every stage of life. Treatment for DCIS does not rule out exercise, and, in fact, it can be helpful. Fatigue is a common result of radiation therapy, but it does not affect everyone. Exercise during radiation can help in all the known ways. In addition, a patient can feel in control by working to stay healthy during treatment. The most important thing is to listen to one's own body and spirit and give each what it wants.

I'm on my bike pedaling to radiation. I spin down the slope toward Golden Gate Park, enter its relative calm, then emerge onto the Panhandle bike path. I smell mown grass and eucalyptus. The watering system sends geysers in huge arcs which smack into me as I duck through them. I feel subtle temperature shifts as I glide between shade and sun along the graceful s-curves. People sleep on the grass. Dog walkers saunter with leashes attached — or not — to dogs of every variety. An old man pushes a supermarket cart with a huge black plastic bag of aluminum cans. Asian elders slowly pirouette through tai chi movements under a shade tree. I leave the Panhandle.

On city streets, I use bike lanes resulting from the time, sweat, and activism of the SF Bicycle Coalition. Bless their perseverance!

I wheel my bike through the lobby of the hospital, down the elevator, and into the radiation oncology department. I morph into a patient, hospital gown and all, for my daily zap. It isn't a bad place, or — now — even a scary one, just dehumanizing. If all goes according to schedule, I'm finished with radiation and back on my bike in twenty-five minutes.

It would be poor form to die coming or going to radiation, so I'm vigilant. On Divisadero, not graced with a bike lane, I swerve to miss potholes and bump over pavement repairs. I avoid shards of red and yellow plastic, debris left by countless fender benders. Buses pass me, spewing diesel fumes; delivery trucks disgorge stacks of brown cardboard boxes; cars maneuver around double-parked cars.

I smile as I return to the Panhandle, gliding along the winding path, surrounded by grass, trees, and normal people doing normal things. Through the Panhandle to Golden Gate Park to the busy Inner Sunset neighborhood, I pedal and breathe and become myself again.

I'm bringing myself back, back up the long hill, back home.



What is it like to go through a course of radiation?

Radiation oncologists know the x-ray dosage required to kill fast-replicating cancer cells, and the dosage tolerated by healthy cells if given in small amounts with sufficient time between treatments to recover. Thus, the number of treatments is determined by dividing the total lethal dose by the tolerable dose. For most patients with DCIS, this involves about twenty-five treatments and five “boost” treatments (radiation aimed at the tumor area rather than the whole breast). This is done over six weeks, once every week day (five treatments a week). A patient usually spends about half an hour in the treatment area per visit, although the actual radiation lasts less than five minutes

Time to transition from cyclist to patient. I lean my bike against the reception area’s aquarium and smile at people waiting there. I enter the treatment area, change into a gown and head for the patients’ waiting room. My radiation therapist, Angela, appears. “Hi, beautiful,” she says. I’m the only one there. She laughs and leads to the tech station. I say my name and birth date; the screen’s picture matches my face. No one else will get what is intended for me.

We go into the inner sanctum, I lie on the gurney, swing my knees over a red bolster, and place my left arm in its rests. There I am, bare-breasted, lycra bike shorts, bike socks and shoes. It’s time to leave my body to the machines.

Angela lines up the green grid with the tattoos on my breast. “All set, perfect,” she announces. “Here comes number seventeen,” and she leaves the room.

The suspended monitor screen is full of data. I’ve figured some things out. When it shows a big green blob, the machine to my right will start buzzing like a very angry swarm of honey bees, a familiar sound from my bee-keeper days. The sound is intense but I feel nothing. The sound stops, the blob goes grey and the machine exhales loudly, as if after major exertion. All this is repeated again, not quite so long this time. Silence. Exhalation. Half over.

The whole machine slowly rotates over my head, and almost disappears below the table on my left side. Same thing on the left side. I still feel absolutely nothing. The monitor flashes back to text, the cursor highlights another name and another face and data screen appears. I’m finished.

Angela returns and lowers the table. I sit up and re-wrap myself in the gown. With a “see you tomorrow,” we part company. I know my way back to the patients’ waiting room. I greet the friendly faces there and disappear into the dressing room.



What is an MRI?

A breast MRI (Magnetic Resonance Imaging) uses magnetic fields to create hundreds of cross-sectional images of the breast. It may be used to view the tissue and any tumors or DCIS in three dimensions. When an intravenous dye is introduced, an MRI shows the path of the dye to determine if there is increased blood supply to a possible tumor since blood flow is a key factor in cancer growth.

There are no known harmful effects from exposure to the magnetic fields that create the MRI images. However, since the examination requires that the patient remain still for about an hour, it can be uncomfortable for some women. Given the length of the examination and the confined space of the machine, some women may benefit from taking a sedative before the study. Expect that the machine will make a loud mechanical noise throughout the examination so earplugs may be helpful. Patients' experiences vary; some women find this to be a difficult test while others fall asleep.



A woman enters an MRI machine for a breast scan, with a technician's help.

It's fall in San Francisco, time for my first six-month follow-up mammogram. I walk through the hospital's front lobby — I love and hate this place. The first four mammograms are ho-hum. But my anxiety meter goes from yellow to red the third time the nurse leaves with more exposures. The friendly radiologist enters and tells me she would like to do a quick ultra-sound. So we go to her machine. We share a silence of concentration, not secrecy. When it is over, she still is not sure and recommends an MRI.

I hate being in cramped spaces so an MRI scares me. I have a pill for anxiety, just in case. The MRI patients' waiting room at the UCSF Parnassus campus is dark. I get a glass of water, drink half of it, then knock the other half onto the rug. A nurse beckons me. I slip the pill under my tongue and change into a hospital gown. She inserts an IV to deliver some dye. I climb up onto a gurney and close my eyes tightly.

Inside the cylinder, the shell touches my body. Metallic clicks are followed by three or four blasts on the horn like a delivery truck backing up. A perky sound clicks like a determined marionette crossing a wooden stage, then a substantial sound churns for about four minutes. All this repeats six times.

Then it's over. The pill — or something — worked. I don't ask the nurse what she saw, and she doesn't volunteer anything. I shed the gown, don my own clothes, and walk home. The next afternoon, my surgeon calls to tell me that all is well. Good to go for another six months. The lump was indeed scar tissue from the surgery.

"I should be thrilled," I say to myself, but feel unhinged. I've lost confidence that I know my own body. Last spring, I thought nothing was wrong. Now, when I am resigned to more DCIS, the test finds nothing there. I'll survive this weird reaction to good news. But this latest scare cut through any remaining shred of invulnerability.

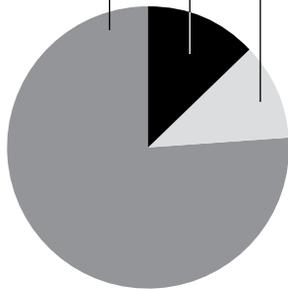


What is the prognosis for DCIS patients?

Five- to ten-year follow-up studies show that, on average:

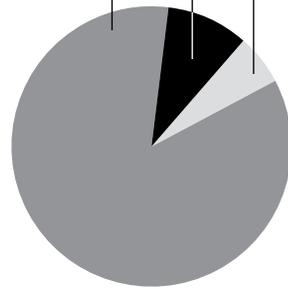
For DCIS patients who choose lumpectomy only

Recurrence as Invasive Cancer (7–14%)
 Recurrence as DCIS (13–14%)
 Recurrence Free (74–78%)



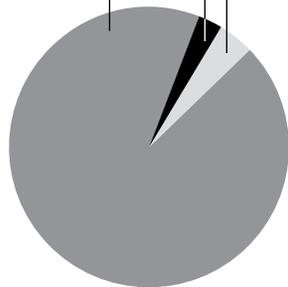
For DCIS patients who have lumpectomy and radiation

Recurrence as Invasive Cancer (4–8%)
 Recurrence as DCIS (4–11%)
 Recurrence Free (84–92%)



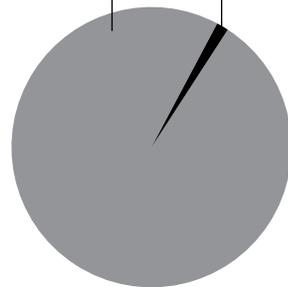
For DCIS patients who have lumpectomy, radiation and take drug therapy (Tamoxifen)

Recurrence as Invasive Cancer (4%)
 Recurrence as DCIS (2–4%)
 Recurrence Free (92–94%)



For DCIS patients who have mastectomy

Disease Recurrence — most recur as invasive cancer (1–2%)
 Recurrence Free (98–99%)



Remember that these numbers are for *all* DCIS. Your surgeon can help you determine your individual risk.

“So what has happened to you in the four years since your diagnosis,” asks Dr. Shelley Hwang. On the health front, absolutely nothing. My DCIS is ancient history. In fact, I don’t think about DCIS at all, except at each follow-up mammogram when I fight off dread.

However, Shelley’s question lingers as I ride the Cinderella Classic. I am one of 2,500 women biking the sixty-seven mile route. It strikes me that this number is a small fraction of the 60,000 women diagnosed with DCIS each year. There are lots of us!

Simple things occur: A rider’s “on your left” isn’t about my lumpectomy; she’s about to pass me. Caring people abound, friendly women riding and friendly men supporting them. When fatigue and hunger stop me so I can gulp down an energy bar, several riders call out, “Are you okay?” I am, totally.

Then flashing lights, an ambulance and a fire truck cluster ahead. As we pedal around them, medics strap a woman in a pink bike jersey onto a back board. I overhear someone say that the patient is lucid. This reassures but soberes me. At any moment, life can come to a screeching halt.

But then an old adage comes to mind: “That which does not kill me strengthens me.” That’s true with my DCIS. Every day I am glad to be alive. My body works as it should, brain, arms and legs, lungs and heart and I don’t take this for granted. The sense that I am not in control of my life, or anyone else’s, has become normal for me. Aging does the same thing, but not with such a wallop.

Of course, each time I look in the mirror after a shower, I see an indentation on a somewhat smaller left breast with a nipple that is withdrawing, seemingly in embarrassment. My husband uses that indentation as a finger-hold when we snuggle before sleep.

And I guess that is the point: We’re shaped — quite literally I’m shaped here — by our experiences. Maybe, just maybe, each one can make us a bit wiser.

USEFUL WEBSITES:

National Cancer Institute (NCI)

cancer.gov — *and enter DCIS in search window*
appliedresearch.cancer.gov/dcis

American Cancer Society

cancer.org — *and enter DCIS in search window*

breastcancer.org

breastcancer.org/dcis_ductal_carcinoma_in_situ.html

Imaginis

www.imaginis.com/breasthealth/dcis.asp

UCSF Helen Diller Family Comprehensive Cancer Center

dcis.ucsf.edu (*this booklet available here as PDF*)
ucsfbreastcarecenter.org

Ida & Joseph Friend Cancer Resource Center

cancer.ucsf.edu/crc

