The Breast Cancer Manual©

Kevin P. Bethke, M.D.
Associate Clinical Director

Northwestern Memorial Hospital
Lynn Sage Comprehensive Breast Center

Patient: _____ Date ____/____/____

For more information and multimedia presentations go to my website:

www.drbethke.com

To-Do List:

1._____
2._____
3. _____
4._____
5. _____
6._____

Comments:

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Welcome:

The fact that you're reading this manual means you've recently been diagnosed with breast cancer.

At the **Lynn Sage Comprehensive Breast Center** we realize how much anxiety this can cause and we will try our best to keep your evaluation and treatment "on track". I like to tell patients that they now have a project and they need to act as the project manager, i.e. stay involved, take notes, ask questions and feel empowered. This **"Manual"** is designed to facilitate your empowerment. You should feel like you're in control of your cancer and not vice-versa.

I've included a number of forms, worksheets and web links designed to help you understand the overall process, expedite your consultations and facilitate decision-making. It is important to remember that breast cancer is **NOT** a medical emergency despite what family and friends may say. However, we do understand that it can feel like an emotional emergency. At times you will feel like the preoperative evaluation is taking forever. You have time to do it right. It is in your best interest to gather as much information as possible prior to deciding a final treatment plan.

Appointments:

I see patients in the Lynn Sage Breast Center on the 4th floor of Prentice Women's Hospital, 250 East Superior Street, Suite 4-420 on Tuesdays, and Fridays. To schedule an appointment please call appointment services at (312) 695-0990

We know your time is important and though we try to be prompt, your appointment may be delayed because of unexpected circumstances. If this should happen, we will attempt to notify you as soon as a significant delay becomes evident.

Teaching:

As a member of the Northwestern Feinberg School of Medicine faculty I have received a number of teaching awards and enjoy my role as a mentor to medical students, surgery residents and breast surgery fellows. Northwestern Memorial Hospital is Northwestern University Feinberg School of Medicine's primary teaching hospital; therefore, trainees (surgical fellows, residents and medical students) may see you while you're a patient. I believe you will find them pleasant and eager to help.

Billing and Insurance:

Northwestern Medicine will send you a monthly statement for your outstanding balance. Prior to your visit please confirm with your insurance company that Northwestern Medicine is included in your plan.

Your insurance plan may require a referral from your primary care physician. It is your responsibility to obtain this prior to your appointment. Many insurance plans require precertification for surgical procedures. Our staff will help you with this process but the ultimate responsibility for proper precertification rests with the patient.

Contact Information:

Lynn Sage Comprehensive Breast Center Scheduling, general information, nursing staff Also use this number for after-hours issues	(312) 695-0990
Kevin P. Bethke, M.D. email (encouraged) Also, MyChart (monitored by nursing staff)	(312) 695-0990 kbethke@nm.org

About Dr. Bethke

Background
I am an Associate Professor of Clinical Surgery at the Northwestern University Feinberg School of Medicine and also the Associate Clinical Director of the Lynn Sage Comprehensive Breast Center and Regional Director of Breast Surgery for Northwestern Medicine. I am currently the elected Chief of Staff at Northwestern Memorial Hospital.

I received my undergraduate degree at St. Olaf College in Minnesota followed by a year at England's Oxford University studying Biomedical Ethics and then Medical School at the University of Minnesota. My General Surgery training was at the University of Wisconsin, Madison and Surgical Oncology fellowship at the Medical College of Virginia.

Specialty and Interests
My practice is limited to breast surgery with a focus on breast cancer. Although providing excellent patient care is my first priority, I also enjoy my role as a teacher and mentor for which I've received numerous teaching awards and am a member of the Department of Surgery's Teaching Hall of Fame. I'm an enthusiastic supporter of research performed at the Lynn Sage Breast Center and actively enroll patients into appropriate research studies.

Contributions to the Medical Field
I've published on a variety of breast disease topics and am a member of many medical societies including the American Society of Breast Surgeons, the Society of Surgical Oncology and I'm a Fellow of the American College of Surgeons. I've been active in many cancer organizations including the American Cancer Society where I served as president of the Downtown Chicago Board.

Approach to Care
I believe in empowering patients by providing them with organized, pertinent information through thorough consultation discussions, email access, worksheets, web links and videos. My hope is that patients will feel comfortable asking any and all questions and feel free to record our consultation with their smartphone. As a surgeon, I strive to not only perform the best cancer operation possible but also to assure the best cosmetic result.

Curriculum Vitae:

Specialty:	Breast Surgery
Undergraduate Education:	St. Olaf College, Northfield, MN, (past member of Board of Regents) Oxford University, England, Biomedical Ethics
Medical Education:	Univ. of Minnesota Medical School, Mpls, 1983
Surgery Residency:	Univ. of Wisconsin, Madison, 1989
Surgical Oncology Fellowship:	Medical College of Virginia, 1991
Academic Appointments:	Associate Professor of Clinical Surgery Northwestern Univ. Feinberg School of Medicine
Board Certification:	Board certified in Surgery, since 1990
Affiliations:	Northwestern Memorial Hospital
Honors and Awards:	"Top Doctors" Castle-Connolly Awards "Top Doctors: Chicago", "Top Doctors: Redbook" "Top Doctors:" Chicago Magazine Patient's Choice: America's Most Compassionate Doctors Award 2011-2020 Outstanding Teacher Award, Northwestern University Dept. of Surgery, annually 2001-2011, 2013-present Member of "Teaching Hall of Fame" Past President, American Cancer Society Chicago Downtown Board
Administrative position:	Associate Clinical Director, Lynn Sage Comprehensive Breast Center Chief of Staff, Northwestern Memorial Hospital

10 Tips for Newly Diagnosed Breast Cancer Patients

1. Don't Panic

Breast cancer is NOT a medical emergency, but it certainly is an emotional one. Take your time, gather the details of your diagnosis, seek whatever opinions you wish and then make a treatment decision that is right for you.

2. Treat this diagnosis as a project and you're the "project manager"

By taking charge as the "project manager" you'll take control of the cancer rather than vice-versa. We'll do most of the work for you but you need to make sure it gets done-you're your own best advocate.

3. Gather ALL of your information

Create a folder or 3-ring binder with ALL of your information: breast imaging reports, lab results, pathology reports, etc. Bring this information to all of your initial physician consultations. Keep a notebook or journal and take notes at each consultation.

4. Don't be afraid of the Internet

The Internet is a great source of information, but it can be overwhelming. Stick to the well-known and trusted sites (see page 7 of this Manual)

5. Choose your physicians (Team) carefully

Caring for cancer takes a **Team** (see page 11). You will have multiple oncologists: surgical (like myself), medical and radiation, radiologists, plastic surgeons, nurses, geneticists, etc. At Northwestern we are all affiliated with the Lynn Sage Breast Center, participate in a weekly multidisciplinary breast conference and all data, reports, and consultations are electronically shared via the electronic medical record (EPIC).

6. Bring someone with you to the initial consultations

There will be a lot of new and unfamiliar information given to you at the initial consultation. You will be understandably anxious and a second pair (or more) of eyes and ears will help you remember and process all of the information later. If you can't bring someone with you feel free to record our conversation.

7. The consultation and treatment process will not always go smoothly

The treatment of cancer is complex, multidisciplinary and requires much coordination. While our goal is to make the process as efficient and streamlined as possible there will invariably be glitches along the way. Have patience and if you think things are not moving as quickly or as smoothly as you think they should please let us know.

8. Don't keep your cancer diagnosis to yourself

It's been my experience that patients who try to keep their diagnosis a secret aren't successful for long. I recommend you share it with your closest friends and family as they may become upset if you don't. This Manual (see page 16-17) has helpful hints for family and friends as they help you through this. Also, there are many support groups available in the community and through Northwestern that we can help identify for you.

9. Everyone's cancer is unique and requires a unique treatment approach

You will receive many opinions and recommendations from family and friends. They mean well but they don't know the special circumstances of your diagnosis. Our goal is to develop a care plan that takes into account all of your special medical information as well as your lifestyle and is one that you are comfortable with.

10. Review the *Breast Cancer Manual* and visit my website www.drbethke.com

Before your surgical oncology consultation with me please review this Manual. It has the information I've referenced in this tip sheet and much more. My website also has more information, web links, videos, and pod casts. The more you know before the consultation the easier it'll be to make treatment decisions.

Web links

Northwestern Memorial Hospital

Home page	www.nm.org
Surgery instructions	Go to Northwestern website www.nm.org and
Patient education	search for specific topic/question

Respected National Cancer Websites

American Cancer Society	www.cancer.org
National Cancer Institute	www.cancer.gov
BreastCancer.org	http://www.breastcancer.org
breast surgery photos	Photos
American Society of Breast Surgery	http://breast360.org

Chicago Area Cancer Support Groups

Cancer Wellness Center Northbrook	www.cancerwellness.org
Gilda's Club Chicago	www.gildasclubchicago.org

Breast Cancer Charities

American Cancer Society	http://www.cancer.org
Northwestern Memorial Foundation	http://giving.nm.org

Step-by-Step Guide for Patients with Newly Diagnosed Breast Cancer

Kevin P. Bethke, MD

I've created this guide to help you navigate the medical system and to make the journey from initial diagnosis to surgical treatment as smooth as possible.

Although you have recently been diagnosed with breast cancer, don't panic. Often the most difficult aspect of being told you have a newly diagnosed breast cancer is fear of the unknown. This guide will help you gather the necessary information, obtain the appropriate tests and consultations and then create an informed and timely treatment plan.

We will need to gather all the pertinent information (mammograms, ultrasound, MRI, pathology results) and then develop a plan that is tailored to your specific circumstances. You'll have plenty of time to ask questions, seek second opinions before arriving at a final treatment plan. Remember, breast cancer is **not a medical emergency** but can feel like an emotional emergency.

Some patients will require many months of therapy after surgery. Therefore, you should look at the entire preoperative evaluation and treatment period as a "project", with you as the "project manager". Although my staff and I are always available to help you throughout this process you are your own best advocate and need to be fully involved in all decisions. One way to help manage all the information and track your test results is to keep everything together in a 3-ring binder or folder.

The nurses at the Lynn Sage Breast Center will be available to answer questions and help coordinate scheduling.

Contact Information:

Lynn Sage Comprehensive Breast Center (appointments, nursing questions and general information)	**(312) 695-0990**
Kevin P. Bethke, MD (email is encouraged)	**(312) 695-0990 kbethke@nm.org**

1. Schedule Appointment

___a. Call (312) 695-0990

____b. The scheduling staff will explain what you need to do before your appointment, and email you detailed instructions. You must follow instructions very closely to prevent delays in your evaluation and treatment.

____c. Once you've made an appointment, one of our Lynn Sage Breast Center staff may contact you to obtain basic information about you and your diagnosis.

2. Breast Imaging

___a. If your breast imaging was performed at Northwestern, our staff will review reports and help determine if additional imaging or biopsies are required. Be aware that the need for additional imaging may not be clear until after you see me in consultation.

____b. If your breast imaging was done elsewhere it will need to be submitted to our radiologists for their review. The Lynn Sage Breast Center staff will instruct you on what studies need to be submitted, and where and how to deliver them. This review can take up to a week or more and once completed it is very likely that our radiologists will recommend additional imaging (mammogram, ultrasound and/or breast MRI) and possibly another biopsy. If additional studies are recommended, the staff will help coordinate this scheduling.

3. Pathology Review

_____a. If your biopsy was done elsewhere you will need to have the actual pathology slides or tissue block delivered to Northwestern for review. The Lynn Sage Breast Center staff will instruct you on what materials need to be submitted, and where and how to deliver them. Once delivered, the materials will be submitted to our pathologists for review and confirmation of the diagnosis. This step is not necessary if your biopsy was performed at Northwestern.

4. Consultation with Dr. Bethke, MD

___a. You will meet with me at the Lynn Sage Comprehensive Breast Center located on the 4th floor of Northwestern's Prentice Women's Hospital.

____b. Many of the usual billing, health information and consent forms will need to be completed for your first visit. These will be emailed to you prior to your visit.

____c. At the time of your consultation you will meet with myself and the nursing staff. You may also meet a Nurse Practitioner, Physician's Assistant, breast surgery fellow, surgical resident or medical student. Northwestern is a teaching institution and you will find the trainees eager to help.

____d. I will review your imaging studies, pathology results, examine you and then we'll review your options together. I may show you your actual imaging studies and I'll use worksheets and possibly photos to help illustrate my recommendation and explain the reasons for them.

____e. If we decide that you need additional breast imaging the Breast Center staff will help coordinate scheduling.

____f. You will have plenty of opportunities to ask questions during and after the consultation.

5. Surgery

____a. Once all studies have been obtained and a decision has been made regarding your best surgical option, my staff will coordinate the scheduling. Prior to surgery you may require:

___Plastic surgery consultation regarding reconstruction options
___Genetic counseling consultation
___Oncofertility consultation
___Medical clearance for surgery from your primary care physician or the Northwestern Surgical Preoperative Clinic
___Consultation with Medical or Radiation Oncology (these consultations usually follow surgery once the final pathology results are available)

____b. My staff will work with you to optimize scheduling. Please realize that the entire pre-operative evaluation can take 2-3 weeks or longer. If you're undergoing immediate reconstruction the surgery date will need to be coordinated with the plastic surgery team.

____c. The final operating room schedule is not available until the day before your surgery. Hospital staff will call you and tell you when to arrive at the Prentice Women's Hospital and give you special preoperative instructions.

____d. Please be patient. The times you're given for surgery are an approximation. Delays can and do occur because preceding operations may take longer than expected for a variety of reasons.

____e. The pathology results will be available approximately 6-7 days after surgery. In most instances I will personally call you with the results.

6. Postoperative Care

____a. A separate postoperative care instruction sheet ("Breast Surgery Discharge Instructions") can be found at the end of this Manual.

____b. I generally see patients 1 ½-2 weeks after surgery. At that time, I will examine the incision(s), remove drains if present and review the pathology report with you. We'll then discuss any further treatment and consultations. There is a good chance that you will need to see both medical oncology, regarding possible chemotherapy and/or hormonal therapy, and radiation oncology regarding postoperative radiation therapy. These consultations usually occur 1-3 weeks after surgery. We will help you see the oncologist of your choice or we'll recommend one for you.

____c. I will follow you for about two years and then you will transition to Northwestern's Survivorship Program. Specialists in the Survivorship Program are trained to monitor you for recurrence and other issues which may arise secondary to your treatment. Our goal is to get you back to a normal life filled with activity, joy and peace of mind.

Your Northwestern Breast Cancer Healthcare Team

Your healthcare team will include a variety of medical professionals. You may not need all these medical providers, but they are all available to you. Once a week our entire team meets as a multidisciplinary group to review the more unusual patient cases and help formulate a treatment plan. All your medical records are easily accessible to members of the team and any Northwestern physician via the Northwestern Electronic Medical Record (EPIC).

Surgical Oncologist (myself): I will lead the preoperative evaluation, perform the appropriate surgery and help plan your follow-up care and other oncology consultations.

Medical Oncologist: A physician who specializes in treating cancer with chemotherapy, endocrine therapy and biological therapy.

Radiation Oncologist: A physician who specializes in treating cancer with radiation.

Plastic Surgeon: A physician who specializes in reconstructing the breast after a mastectomy.

Breast Radiologist: A physician who specializes in screening for breast cancer, diagnosing breast cancer with image-guided needle biopsy and preoperative planning using mammography, ultrasound MRI and other techniques.

Breast Pathologist: A physician who specializes in the evaluation and identification of breast tissue abnormalities. They microscopically review all needle biopsy and surgical specimens and provide the diagnosis.

Oncology nurse: A physician who provides care, support and education during your cancer treatment.

Nurse Practitioner or Physician's Assistant: Advanced practice providers with a special interest in breast diseases who may see you in the clinic and assist in the OR.

Nurse Navigator: An RN who can assist you at every stage of your cancer care, from scheduling treatments to accessing social and financial resources.

Social worker: A professional who can help you deal with psychological and social issues as well as financial concerns, including insurance matters.

Rehabilitation specialist: (physical or occupational therapist)-a professional who can assist with restoring or improving movement and help you more easily perform daily activities.

Cancer Geneticist: A professional who specializes in diagnosing inheritable cancer syndromes such as the BRCA (breast cancer) gene mutation which predisposes one to a higher risk for breast and ovarian cancer.

Oncofertility specialist: Physicians and other healthcare professionals who can help you with fertility issues which arise before, during and after cancer treatment

Cancer Survivorship Specialist: Northwestern has created the Northwestern Survivorship Institute to care for our many cancer survivors. Their goal is to recognize and treat any special needs related to cancer therapy and help our survivors return to their active, joyful lives.

Breast Cancer Treatment Worksheet

Patient name: _____ Date: ___/___/___ Age: _____

Pathology

Invasive cancer: *Infiltrating ductal* *Infiltrating lobular* *Mixed*
Non-invasive cancer: *DCIS (Ductal Carcinoma In-Situ)*

Grade: *1 2 3* Estrogen receptor: *positive negative*
Side: *Right Left* Her 2: *positive negative*

Comments: _____
_____
_____

Treatment Options:

A. Breast Conservation (generally referred to as a *Lumpectomy*):

In order to be a candidate for breast conservation the cancer needs to be localized to a relatively small area of the breast so that we can encompass it with a lumpectomy, obtain clear margins and still have enough breast tissue left such that there is no major deformity.

The components of Breast Conservation include: (usually performed as an outpatient under twilight anesthesia)

1. Lumpectomy: (with preoperative localization using a wire or seed if cancer cannot be felt on exam). About 10% of the time the margins are found to be microscopically positive on final pathologic review and a second (30-45 min) procedure several weeks later is then necessary to remove more tissue and clear the margins. Pathology results are available 6-7 days after surgery.

2. Sentinel lymph node biopsy: Sentinel node biopsy is not necessary for most noninvasive cancers (DCIS) but it is for invasive cancers. Generally, 1-5 (ave=3) sentinel nodes are identified with radioactive dye and removed and reviewed by the Pathology Lab. If the nodes do not contain cancer, then no further surgery under the arm is necessary. If the nodes are positive for cancer cells then a follow-up axillary dissection may be necessary, however the trend is to do fewer axillary dissections.

3. Axillary Dissection: This is the removal of additional lymph nodes and may be required if your sentinel nodes contain cancer. If performed, a small drain will be placed under the arm and it will remain in place for 10-14 days. This procedure raises the risk of lymphedema (arm swelling) to approximately 15-20%, compared to sentinel node biopsy alone which has a 2-3% risk of lymphedema.

4. Radiation Therapy: Lumpectomy patients generally require postoperative radiation therapy to the entire breast, which is given 5 days/week for 3 ½ to 6 weeks and each treatment lasts about 5 minutes. Some patients, > age 70 with small, slow-growing cancers may not require radiation. You will consult with a **Radiation Oncologist** after surgery and they will recommend a radiation treatment plan for you.

5. Systemic Therapy: Systemic therapy includes chemotherapy which is a combination of drugs given intravenously to kill any cells that may have escaped to other parts of the body prior to surgery. Other forms of systemic therapy include hormonal therapy (such as Tamoxifen or Arimidex) and biological therapy (such as Herceptin and Perjeta). The recommendation for systemic therapy is made by the **Medical Oncologist** and depends on a number of factors such as patient age, size of tumor, lymph node involvement, grade, estrogen receptor and Her2 status, Oncotype testing, etc. Radiation therapy and systemic therapy have different goals and are not mutually exclusive. For certain cancers chemotherapy may be recommended to be given before surgery.

B. Mastectomy:

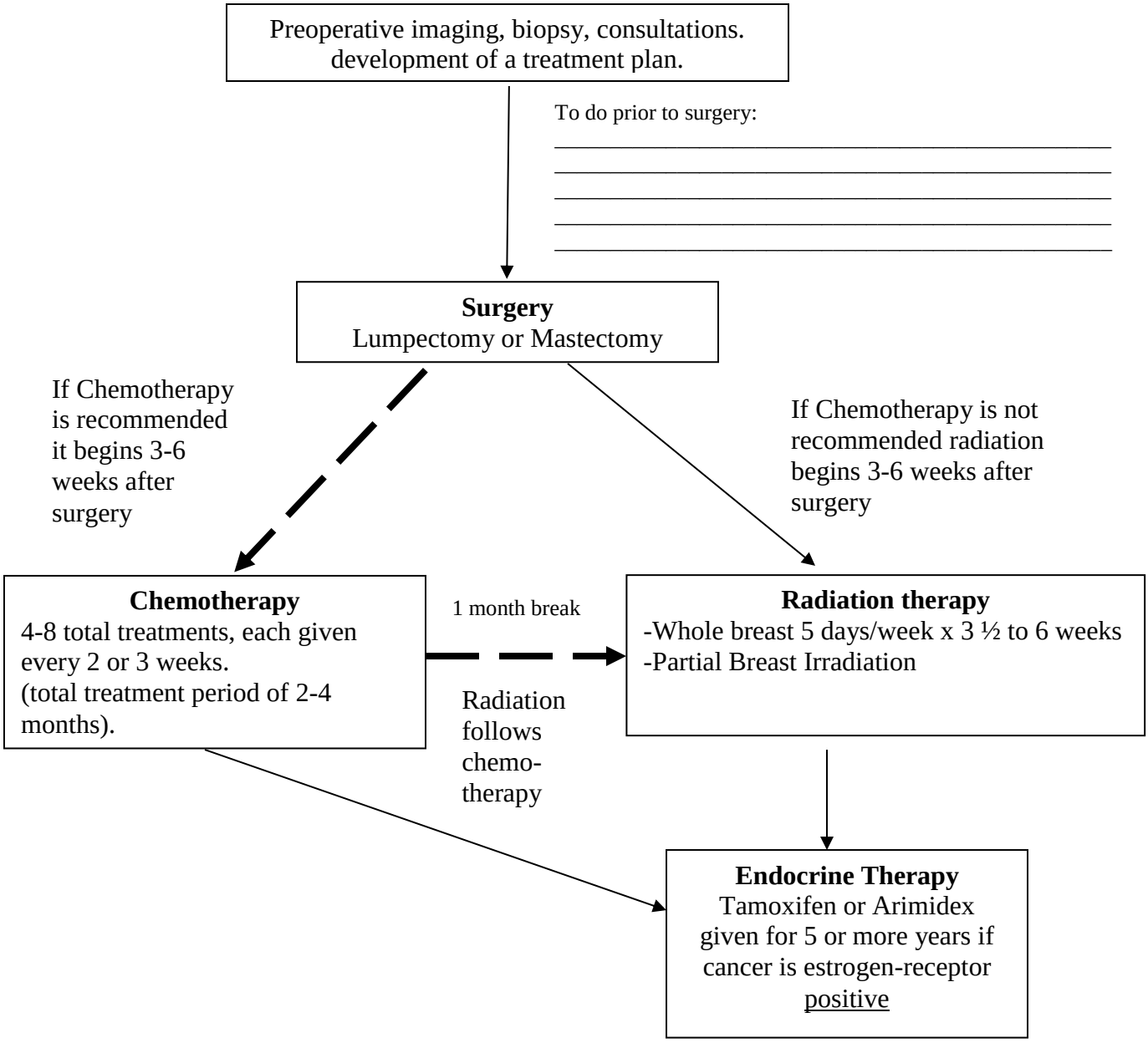
Patients who have very large cancers or cancer cells scattered over a large portion of the breast are not candidates for breast conservation and therefore require a mastectomy: Some patients may prefer a mastectomy even if they are a candidate for breast conservation. Radiation is usually not necessary after a mastectomy. Mastectomy options include:

1. **Skin-sparing mastectomy with immediate reconstruction:** Most of the breast skin is preserved but the nipple-areolar complex is removed. After the mastectomy and sentinel lymph node biopsy is completed the Plastic Surgery team comes into the operating room and performs the first phase of the immediate reconstruction. You will meet with your **Plastic Surgeon** prior to the day of surgery to decide the appropriate reconstruction technique. Options include temporary expander followed by permanent implant, immediate permanent implant, TRAM (DIEP) flap or latissimus dorsi flap.
2. **Nipple-sparing mastectomy:** Patients may be candidates for nipple-sparing mastectomy if they have small breasts (A or B cup), it is a prophylactic mastectomy, or the cancer is small and not close to the nipple. If the breast is large, the blood supply to the nipple-areola complex may be inadequate and the nipple may not survive. If the cancer is too close to the nipple area there may be a higher risk of recurrence. As in all forms of mastectomy there is permanent numbness over the central breast and no sensation to the nipple if it is preserved.
3. **Traditional mastectomy without reconstruction:** If a patient chooses this option, she will have a flat chest on the side of the mastectomy and can wear a prosthesis that fits inside her bra.

When a mastectomy is performed, postoperative radiation is generally not necessary unless the cancer is quite large, lymph nodes are involved with cancer or margins are close or positive. The recommendation for chemotherapy is the same whether one chooses breast conservation or a mastectomy. A mastectomy without reconstruction or with expander reconstruction generally requires an overnight stay in the hospital. When the reconstruction is performed with your own tissue (TRAM flap or latissimus flap) the hospital stay is generally several days.

The overall survival is exactly the same whether breast conservation or a mastectomy is performed. The risk of the cancer returning within the affected breast or on the chest wall is approximately 5-6% for breast conservation and 2-3% for a mastectomy. If the cancer recurs in the breast after a lumpectomy and radiation a mastectomy is generally required to treat the recurrence.

Timeline (traditional, surgery first):



***Breast cancer is NOT a medical emergency but it often feels like an emotional emergency*.**
You have time to gather all the necessary information, obtain a complete breast imaging evaluation and seek second opinions if you wish. You need to make sure that you are comfortable with your physicians and your decisions before proceeding.

Follow-up Care:

Following your breast surgery, I will see you 1-3 weeks after surgery, 6 months after surgery and 18 months after surgery. After a couple years the Northwestern Survivorship program will follow you. The Medical Oncologist will follow you for 5 years or more. You may have three different oncologists-Surgical, Medical (in charge of chemotherapy and perhaps hormonal therapy) and Radiation. If you underwent breast conservation surgery (lumpectomy) you will obtain a mammogram on the affected breast about 6 months after completion of radiation and then yearly.

Services offered by the Lynn Sage Comprehensive Breast Center, the Lurie Cancer Center and Northwestern Memorial Hospital

Oncofertility Program

For patients concerned about fertility issues during and after their breast cancer treatment.

Breast Cancer Survivorship Program

The SUCCEED Program focuses on surveillance and early detection of cancer recurrence, treatment of after-effects of therapy, psychological and wellness concerns, as well as strategies for healthy living.

Reproductive Genetics, Hereditary Cancer Services

Provides hereditary cancer risk assessment, genetic testing, cancer screening recommendations and an ovarian cancer screening program.

Rehabilitation Services

Provides pre-surgical classes, education on exercise programs after surgery and lymphedema prevention counseling and treatment.

Program 360

An Integrative Medicine program that combines conventional and complementary therapies to aid in your healing process. It engages the mind, body, spirit and community while focusing on lifestyle choices.

What to do, and what not to do, when your friend is diagnosed with breast cancer

Here is some guidance for that first dreadful moment when you learn that someone you care about has breast cancer.

DO.....

- Send cards and emails. Just a short little note will do. She isn't scrutinizing your words; she is just happy to know that another person is rooting for her.
- Make sure she knows you do not expect a reply to emails or phone calls.
- Send a card addressed specifically to her husband or partner. They need attention and support too.
- Send along any information about local doctors. A good referral can help her feel more confident in her choices. But once she has made her choice, support her decision.
- Take her kids somewhere fun so she can return calls and talk openly. The weeks just after a diagnosis involve many decisions that require much discussion and consideration. Kids can make that very difficult.
- Offer to spread the word for her to anyone in particular she wants to know. She may feel guilty that she is unable to call certain people personally. It will ease her mind if you can call special friends and gently share her news.
- Volunteer to do specific tasks, like bringing dinner by or dropping off some groceries.

DON'T.....

- Be afraid to reach out even if you don't know her well. A card is always appreciated.
- Ask for too much detail or explanation; she is reporting out to many people and may need a break.
- Expect her to call you back promptly.

BE AWARE.....

- In the early days, she may feel cut off by comments like: "My friend had breast cancer two years ago and she's fine!"
- Some books, like Lance Armstrong's, might overwhelm her. His cancer was extreme and his chemo experience may scare her.
- Every message counts. Your note or call may not feel like much to you, but combined with every other note or call she gets, it becomes a tidal wave of support to carry her from the initial shock into the beginning of treatment.

Talking to Your Friend

If you feel nervous about talking with your friend, here are some pointers from cancer patients.

Be yourself and don't be afraid.
Your friend doesn't expect perfection. Some people have a knack for expression, some people are lost. Your friend sees that you care and that you are doing your best.

Don't push advice.
You probably don't know enough about her case to really be useful. It can be tiresome to hear "My friend Paula had breast cancer and she said that her doctors recommended chemo every week…"

When in doubt, email an offer of help or companionship.
Unreturned phone calls can be a weight on your friend. Also, the phone ringing might wake her up or force her to think about cancer during a time when she is not. Always end a message with "No need to reply; I am just thinking about you."

Listen more than you talk.
You are there for her. Give her some runway to talk about whatever's on her mind …an annoying insurance problem, a funny card she got, an aching back, her old car that isn't selling.

Don't force the cancer conversation.
If she's trying to talk about her husband's nasty boss, and you came to get the latest update on her treatment, stick with the nasty boss stories. Cancer isn't the only thing going on her life.

Don't expect her to follow up on every suggestion.
Many people will suggest that she call their friend who had breast cancer or read a new article about an ongoing clinical trial. These can be very helpful, but can also feel like another thing for the To Do list. Just pass the info along in a card or email and leave it there.

Focus. Take off your coat, sit down, turn off your cell phone. If your friend starts to open up and vent, stay with her. It helps to tell your friend up front how long you can spend so she doesn't worry that her mood sent you packing.

Don't rush her through the hard stuff. Your friend is sick, scared, bald, uncomfortable, and tired. Try not to quickly stifle these truths with platitudes like, "You've got to stay positive" and "This is going to be over soon". Let her complain and cry and feel a little self-pity before you start to help her put herself back together again.

Respect her experience. Don't say, "I know how you feel" unless you actually do. Don't say "My friend had the exact same thing and she's doing great." Every cancer case has unique elements.

Taken from Circus Of Cancer, www.circusofcancer.org, a how-to-site to help you step right up when your friend has breast cancer.

Breast Surgery
Post-operative Instructions
Lumpectomy, Mastectomy, Axillary Dissection

Kevin P. Bethke, MD

The following instructions will provide helpful information that will assist your recovery. These are designed to be general guidelines. Remember, everyone recovers differently. Listen to your body and rest when you are tired. If you have any questions or concerns, please contact my staff or myself.

Expected Reactions

- Mild-moderate discomfort/pain at the surgery site. This gradually improves over several weeks, but it is not uncommon to feel intermittent twinges of pain, tingling, or a burning sensation even months after the surgery as your body heals.
- You may experience numbness in the arm and shoulder area if you had surgery to check the lymph nodes. This will gradually decrease but can last for several months.
- Mild swelling and/or bruising at the surgical site and incision area.
- Small amount of drainage from the incision.

Restrictions

- There are no lifting weight restrictions for the arm on the surgical side. You may gradually increase the amount of weight based on your comfort level. You should avoid a lot of repetitious activity with the arm until the drain is out (if one was placed) and the wound is well-healed (about two weeks).
- You should not drive a car until you believe you can react to an emergency situation and you're no longer taking narcotic pain medications.
- You may shower the day after surgery. You should not bathe or swim (i.e. submerge wound) until the wound is well healed (about two weeks).
- If you had reconstruction your Plastic Surgeon may have specific restrictions-check with them first.

Exercise

- You may begin arm exercises within a couple days. Do these 2 or 3 times per day, beginning with light exercise and gradually increase your range of motion and repetitions. This will help your arm regain full mobility.
- You will have pain medication prescribed before discharge. Take this as directed to relieve pain. It is important that you be comfortable so that you may continue your stretching exercises.
- If you find the medication prescribed is too strong, try Tylenol (acetaminophen) or ibuprofen.
- If you feel that your range of motion is not improving as quickly as you would like, please let our nursing staff know and they can order physical therapy for you.

Wound Care

- You may remove the gauze dressing on the first or second postoperative day and then shower.
- You should replace gauze dressing on the wound until the wound is completely dry and without drainage-usually 1-3 days.
- The steri-strips (narrow white tape strip over incision) should be left on for 10 days and then you may remove if you wish or leave them on until they fall off. If they come off before 10 days don't worry, there are two layers of absorbable sutures under the skin.

- If an elastic bandage was placed around your chest after the surgery you may remove it on the 1st or 2nd day after surgery. If you prefer to leave it on longer, you may.
- You may wear a bra. Sport bras are usually the most comfortable and give the best support. If the breast doesn't move it is less painful.

Drain Care (if placed at time of axillary dissection or mastectomy)

- Empty the drain and **strip** the tubing 2-3 times daily, more often if the plastic squeeze bottle fills up. This will prevent the tubing from clogging.
  - Starting at the top of the tubing next to your body firmly grasp the tubing with the index finger and thumb of one hand. With the other hand use the index finger and thumb to move the fluid down the tubing (this is called "stripping the tubing").
  - Uncap the pouring spout and squeeze the contents of the plastic bottle into the measuring cup.
  - Squeeze the bottle **flat** to create suction and replace the cap while squeezing to maintain the vacuum.
  - Measure and record the output and discard the fluid into the toilet. Record the output each time you empty the bottle.
  - Keep track of the output (drainage) and when the total is down to 30 cc's or less over a 24-hour period we'll remove the drain in the office.
  - Drain removal takes about 30 seconds and is virtually painless. The suture is cut and the drain easily slides out. You should call the Breast Center as the output approaches 30 cc's over 24 hours so that we may schedule an office visit for drain removal.

Pain Medication

You will be given a prescription for a pain medication (generally Tramadol) upon discharge. Many patients have very little pain and don't want to use the Tramadol. Don't be afraid to use it if you're uncomfortable. You may want to take it before bedtime to improve sleep. If you'd prefer, you may substitute Tylenol or ibuprofen (Motrin, Advil).

Pathology Report

The Pathology report is usually available 6-7 days following your surgery. I will call you with the results once the report is available.

Notify the Lynn Sage Breast Center if:

- Your temperature is over 101.5 F.
- You notice increasing swelling, redness, warmth or drainage from around the incision or drain site.

If you experience any problems, please call the Lynn Sage Breast Center 24/7 and either a nurse or the physician on call will respond.

Lynn Sage Breast Center (312) 695-0990

(nursing and answering service)

If you experience healing issues after reconstruction you should call your Plastic Surgeon.

Breast Reconstruction Options

American Society of Plastic Surgery

For a thorough discussion of reconstructive options and multimedia presentations with photos, videos and realistic expectations please go to the American Society of Plastic Surgery website (below)

http://www.plasticsurgery.org/Reconstructive-Procedures/Breast-Reconstruction.html

If your breast cancer is quite large relative to your breast size or the cancer is scattered throughout your breast you will not have the option of a lumpectomy and you will require a mastectomy, either with or without immediate reconstruction. Also, some patients may choose a mastectomy even though they are candidates for a lumpectomy.

The overall survival is the same whether you have a mastectomy or a lumpectomy with follow-up radiation therapy. The risk of a local recurrence (recurring near the lumpectomy site) after a lumpectomy and radiation therapy is about 5-6% versus about 3% with a mastectomy. If you initially underwent lumpectomy and radiation therapy and then had a recurrence you would most likely require a subsequent mastectomy.

Once I complete the mastectomy the Plastic Surgery team comes into the operating room and performs the first phase of the immediate reconstruction. This is done by filling the space between the preserved skin and chest wall, either with a temporary expander that is later replaced with a permanent implant or with your own tissue. If you don't undergo immediate reconstruction your chest will be flat, and you can then wear a prosthesis inside your bra to achieve form and symmetry.

There are 3 main types of reconstruction techniques:

1. Temporary expander followed by a permanent implant (or direct to permanent implant)
2. DIEP/TRAM flap or a variation (taking tissue from lower abdominal wall).
3. Latissimus flap (using tissue from your back and swinging it around to the chest)

These reconstructive techniques are combined with either a skin-sparing mastectomy (standard procedure removing nipple-areolar complex but preserving skin) or a nipple-sparing mastectomy.

Generally, the more complex the surgery the more natural the look and feel of the reconstruction. Often a breast reduction and/or lift of the opposite breast may be required to achieve symmetry. Prior to making any decisions on reconstruction you will meet with the Plastic Surgeon and they will carefully review with you the various options and together the two of you will decide the best option for you. A federal law was passed many years ago which indicates that reconstruction (and opposite breast symmetry procedures) must be covered by insurance.

Reconstruction Procedures

1. Expander/implant reconstruction

Advantages

-Least invasive surgery
-No additional scars
-Advantages greater with bilateral reconstruction

Disadvantages

-Two step procedure: temporary expander at initial surgery
followed by a permanent implant at a later time
-May be difficult to match opposite side
-Greater risk of infection and overlying skin loss
-Difficult to obtain normal tear drop shape of breast

2. DIEP/TRAM flap reconstruction

-Muscle and skin from the lower abdomen is used to fill the space created by the mastectomy
-Variations include pedicled, free, DIEP and muscle-sparing

Advantages:

-One stage
-Most natural shape and feel
-Also get abdominoplasty (tummy tuck)

Disadvantages:

-Most invasive, longest recovery
-Abdominal scar
-Can develop fat necrosis of tissue (lumpiness)

3. Latissimus flap reconstruction

Advantages

-Intermediate surgery
-One stage reconstruction
-Intermediate result

Disadvantages

-Scar on back
-Usually requires an implant in addition to flap for optimal breast size
-Infection risk with implant
-Muscle and nerve division

Nipple-Sparing Mastectomy

With a nipple-sparing mastectomy the nipple-areolar complex is preserved rather than removed as in a standard skin-sparing mastectomy. In both types of mastectomy all of the breast tissue from the lower fold of the breast to the collarbone and from the mid chest (sternum) to the lateral chest is removed.

Nipple-sparing mastectomies are a relatively new concept. There has always been some concern about a higher risk of the cancer recurring in the nipple-areolar area if it is preserved. So far, research has not shown this to be a problem if used for prophylactic mastectomies or in patients with small cancers located a distance from the nipple.

Advantage of nipple-sparing mastectomy:

-Best cosmetic result

Disadvantages of nipple-sparing mastectomy:

-Theoretical higher risk of cancer recurrence but so far literature has not demonstrated a significant increased risk

-Literature shows about a 5% risk of necrosis (skin death) with nipple-sparring technique. The nipple-areolar complex is then removed, and you end up with a skin-sparing mastectomy.

-Nipple has no sensation (there is always a strip of numbness across the chest with any mastectomy).

-The nipple may lose its protrusion and the areolar may fade slightly over time.

Day of Surgery Schedule

This is what your day will look like whether your surgery is outpatient or you will be admitted afterwards. The Operating Room staff will call you the day before surgery and let you know what you need to do the evening before surgery and when to arrive at the hospital.

1. You will either check-in at the 6th floor Prentice preoperative area or the 4th floor Prentice Breast Imaging Department (if you are having preoperative wire localization).
2. In the pre-op area:
    a. The **nursing staff** will check you in and pack your clothes and valuables for safe storage.
    b. An **IV** will be started.
    c. The **surgery team** (myself, medical student, resident breast surgery fellow, Physician's Assistant) will see you and your family and have you sign the surgical consent form. I will initial the side that we're operating on (Joint Commission rules to prevent wrong-sided surgery) and answer any questions.
    d. The **anesthesia team** (anesthesiologist, nurse anesthetist, anesthesia resident) will see you, explain the anesthesia and have you sign their consent form.
    e. If you're having a sentinel node biopsy the **nuclear medicine team** will inject the radioactive dye.
    f. If you're having immediate reconstruction the **plastic surgery team** will see you and they may draw their planned incisions on your breast.
3. The **time of surgery is an estimate** and there may be delays for many reasons (the prior surgery in your OR was more difficult and took longer than expected, guide wire placement took longer than expected, difficult IV placement, etc.).
4. While you are in surgery your family and friends may wait in the **family waiting area (6th floor**). The nursing staff will show them where to go. We will also have their phone number in the event they are not present for me to meet with them at the completion of your surgery. If they wish to get something to eat or have some coffee there is a wide variety of options at Northwestern.
5. I will speak with your family and friends once I have completed your surgery, **however, I may not be able to speak to you after your surgery** because I generally have 4-6 operations/day and go right back to the operating room with another case once I finish your surgery. If I do speak to you in the recovery area you may not remember because you were still sleepy from the anesthesia.
6. The **plastic surgeon** will speak to your family when they finish their reconstruction procedure.
7. On long operations the OR nursing team will try their best to call your family **every 2 hours** with an update.
8. If you had a **general anesthetic** for an outpatient procedure you will be in recovery for about 2 hours and your family may join you after about 1 ½ hours. You will be given written discharge instructions. If you are admitted to the hospital after surgery you will be moved to an upper level floor in Prentice.
9. If your **outpatient surgery** was performed with monitored anesthesia care (twilight sedation) your family may join you 10-15 minutes after surgery (the nursing staff will bring them to your recovery room) and you will be discharged home with written instructions after about 1 hour
10. If you are **admitted** overnight the breast surgery team (breast surgery fellow, surgical resident, Physician's Assistant) will see you the following morning, assess your recovery and complete the discharge orders and instructions. If you had reconstruction the plastic surgery team will also see you in the morning. If you had a drain placed the nursing staff will teach you and your family how to care for it.
11. I will call you once the **pathology results** become available (about 6-7 days)

If you have problems don't hesitate to call the Lynn Sage Breast Center staff at (312) 695-0990