Axillary Lymph Node Surgery Education
Including Breast and Melanoma Surgery
Dear Axillary Lymph Node Surgery Patient,

As part of your cancer surgery, you may have lymph nodes removed from your armpit or axilla. Surgery is the first step of treatment, now it is time to focus on recovery. The information outlined in this booklet will help you progress through the physical aspects of recovery, which will eventually allow you to return to normal activities. It is also important to be aware of the risk of developing lymphedema since some of your axillary lymph nodes have been removed.

We feel it is important to be knowledgeable about your disease, surgery, treatment, and recovery. This will allow you to participate in your care, while restoring a sense of control. Seek answers from your healthcare team.

We encourage you to use this booklet throughout all your treatments and to add to it as your recovery progresses. In addition to your healthcare team, there are many services available through the nationally accredited John Stoddard Cancer Center listed under the reference section.

We hope to be your resource for a successful recovery. If you have questions, please contact your physician or the Lymphedema Clinic.

Sincerely,

The Lymphedema Clinic
John Stoddard Cancer Center
Iowa Methodist Medical Center
515-241-6839

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## Post-Axillary Lymph Node Surgery Education

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# CANCER RESOURCES

## Stoddard Directory

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<td>(515) 241-8700</td>
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<td>Adult Oncology Social Services</td>
<td>(515) 241-6105</td>
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<td>Blank Children’s Cancer Center (Inpatient)</td>
<td>(515) 241-8100</td>
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<tr>
<td>Breast Cancer Care Coordinator</td>
<td>(515) 241-4248</td>
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<tr>
<td>Cancer Information Line</td>
<td>(515) 241-4141</td>
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<tr>
<td>Chaplain</td>
<td>(515) 241-6411</td>
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<tr>
<td>Executive Director</td>
<td>(515) 241-4336</td>
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<td>General Information</td>
<td>(515) 241-4141</td>
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<tr>
<td>Genetic Counselor</td>
<td>(515) 241-3343</td>
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<td>UnityPoint at Home</td>
<td>(515) 577-3100 or (888) 584-6311</td>
</tr>
<tr>
<td>Look Good…Feel Better</td>
<td>(515) 241-4243</td>
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<tr>
<td>Lymphedema Clinic</td>
<td>(515) 241-6839</td>
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<tr>
<td>My Nurse</td>
<td>(800) 424-3258</td>
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<td>Oncology Dietitian</td>
<td>(515) 241-3310</td>
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<tr>
<td>Oncology Outreach Coordinator</td>
<td>(515) 241-8505</td>
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<tr>
<td>Oncology Registry and Statistics</td>
<td>(515) 241-4245</td>
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<tr>
<td>Outpatient Services Manager</td>
<td>(515) 241-4395</td>
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<tr>
<td>Radiation Oncology</td>
<td>(515) 241-4330</td>
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<tr>
<td>Research Coordinator</td>
<td>(515) 241-8704</td>
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<td>Ronald McDonald House</td>
<td>(515) 243-2111</td>
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<td>Pediatric Oncology Outpatient Services</td>
<td>(515) 241-6000</td>
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<td>Pediatric Social Services</td>
<td>(515) 241-5554</td>
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<td>Taylor House Hospice</td>
<td>(515) 557-3111</td>
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The John Stoddard Cancer Center offers many support services to patients and families who wish to share their feelings with others who will understand. The staff at the John Stoddard Cancer Center believes that a caring, supportive environment is important for the mental well-being of patients with cancer and their families and friends. For more information on these and other support programs at the John Stoddard Cancer Center, please call (515) 241-3343. Here are some of the support programs and services that are available:

**SUPPORT GROUPS**

**ADVANCED OR RECURRENT BREAST CANCER GROUP:** For anyone whose breast cancer has recurred or advanced to Stage IV.

**ADVANCED OR RECURRENT CANCER SUPPORT GROUP:** For anyone whose cancer has progressed to Stage IV.

**AFTER BREAST CANCER (ABC) SUPPORT GROUP:** A group providing emotional, educational, and practical support to women confronting breast cancer.

**BLOOD CANCER FAMILY SUPPORT GROUP:** For adult patients with leukemia, lymphoma, Hodgkin’s disease, myeloma or myelodysplastic syndromes and their family and friends.

**BRAIN TUMOR SUPPORT GROUP:** For persons with brain tumors as well as their family and friends.

**CAREGIVER SUPPORT GROUP:** A blend of open discussion as well as educational information to help with practical advice and guidance from both healthcare professionals and other caregivers.

**COLORECTAL CANCER SUPPORT GROUP:** For patients and their family members and friends. Throughout the year, each member of the JSCC colorectal cancer multidisciplinary team will speak to the group.

**EmPowered:** A support and education system for young women at high risk for breast and ovarian cancer.

**GETTING STARTED – CHEMOTHERAPY:** For all new cancer patients and their families, as well as for those currently undergoing chemotherapy. Learn what you should know about chemotherapy and what to expect during and after treatment.

**GYNECOLOGIC CANCER SUPPORT GROUP:** For persons with ovarian or any type of gynecological cancer and survivors as well as their families and friends.

**LUNG CANCER SUPPORT GROUP:** For patients and their family members and friends.

**OSTOMY SUPPORT GROUP:** This support group is open to persons with ostomies as well as their family and friends.

**PROSTATE CANCER SUPPORT GROUP (Us TOO):** A national support group for prostate cancer survivors and their families that offers information, counseling and educational meetings.

**SUPPORT FOR PEOPLE WITH ORAL, HEAD & NECK CANCER (SPOHNC):** For anybody that has a diagnosis of oral, head or neck cancer. This group is open to patients that are newly diagnosed, currently getting treatment, have completed treatment or at any stage in their cancer journey and to their family members.
INDIVIDUAL CONSULTATIONS

WHAT’S ON YOUR MIND?: A group or individual counseling program for people with cancer and/or families. Patients/family members are welcome to come to group counseling or may set up individual appointments.

LOOK GOOD…FEEL BETTER: Designed for people undergoing chemotherapy or radiation treatments. Wigs, turbans, and makeup tips are available. Individual consultations or group classes are available.

REACH TO RECOVERY: A visitation program for women with a personal concern about breast cancer. For more information, call the American Cancer Society toll-free at 1-800-ACS-2345.

ADDITIONAL SERVICES

CANCER HELP ™: Interactive kiosk designed to help patients and their family members take an active part in treatment and to learn about side effects, medication information, support services, diet & nutrition, clinical trials, etc. John Stoddard Adult Oncology Inpatient Unit located on Powell 3.

FAMILY RESOURCE LIBRARY: Information available regarding cancer and community resources—videos, audiocassettes, books, and brochures. The library is located on the first floor of Blank Children’s Hospital. There are additional materials (pamphlets, brochures, support group information) located on the 4th floor of the John Stoddard Cancer Center.

LIFE BEYOND BREAST CANCER: A six-week program for women who have recently completed breast cancer treatment. Beginning dates for upcoming sessions and registration information will be listed in the Classes and Events section at www.johnstoddardcancer.org. There is no fee to participate and a physician’s referral is not required. A few of the topics that will be covered include: nutrition and weight management, the benefits of yoga, long-term side effects of treatment, relaxation techniques, relationships and coping skills.
Adolescent and Young Adult (AYA) Cancer Program - A program for cancer patients ages 15-35 to provide age-specific care during diagnosis, treatment and recovery. AYA cancer patients require a broader scope of care than any other population because of the many physical, emotional, developmental and social changes they experience on a regular basis. Despite survival rates dramatically increasing for children and older adults, survival rates for this age group have had minimal improvements over the past 20 years. The John Stoddard Cancer Center and Blank Children’s Hospital have partnered to develop a program to improve AYA outcomes. This includes promoting better participation in clinical trials, more knowledge on the biological differences of the disease, greater access to resources and health care. For more information, please call (515) 241-4251.

Stoddard Care Coordinator – A cancer care coordinator’s main purpose is to help coordinate quality care and support for the patient and their loved ones. This entails developing and overseeing the care patients receive from diagnosis to treatment and beyond. The coordinator assesses patient’s needs, and implements quality improvement initiatives and referrals by involving multidisciplinary team members from the John Stoddard Cancer Center. Care coordinators work to enhance patient and family education. They proactively work to provide good symptom management for each patient with cancer and they are a strong patient advocate for the patient and their families. For more information about our care coordinators, please call (515) 241-3343.

Genetic Testing - The John Stoddard Cancer Center established the genetic testing program to help central Iowans evaluate their personal risk for developing cancer and to learn about steps they can take to prevent it. Through a simple blood test, we can determine whether or not individuals carry a mutated gene that causes breast, ovarian or colorectal cancer, or are at higher risk for related cancers. Genetic testing is designed for individuals who may be at an increased risk of cancer due to a medical or genetic condition, or those that have multiple occurrences of cancer in their family (i.e., a family history of breast cancer). If an individual tests "positive" for the genetic mutation, an appropriate risk reduction plan is developed with a trained counselor. This may include careful monitoring or periodic screening tests, changes in diet, exercise or other lifestyle factors, and the use of cancer prevention agents. For more information on genetic testing or to make an appointment, please call the Oncology Research Coordinator at (515) 241-8704.

Ovarian Cancer Screening Trials - The John Stoddard Cancer Center recently teamed up with the M.D. Anderson Cancer Center and Massachusetts General Hospital to offer ovarian cancer screening trials, which are designed to detect cancer earlier in women at risk for ovarian cancer. The National Cancer Institute ranks ovarian cancer incidence fifth among women in the United States. These trials are extremely important because ovarian cancer is not always hereditary, nor are there any obvious presenting symptoms. There are no proven methods of preventing ovarian cancer and it is often a rapidly progressive disease. Women who are diagnosed early have a higher survival rate. For more information on ovarian cancer screening trials, contact the oncology research coordinator at (515) 241-8704.

Clinical Trial Participation - Research plays a large role in cancer care. Through research we have identified improved methods of treating patients. Over the years we have been able to diagnose cancers earlier and provide better outcomes and survival for our patients. With continued investment in research, we look forward to the day that we can say we have a cure for cancer. The Iowa Oncology Research Association (IORA) physicians have over 100 clinical trials available covering all areas of cancer treatment. Areas of research include: chemotherapy, radiation therapy, immunotherapy, surgery, cancer control (symptom management) and cancer prevention. They also participate in cancer prevention trials including the National Breast Cancer Prevention Trials (BCPT and STAR) and the National Prostate Cancer Prevention Trials (PCPT and Select). Clinical trials offer high-quality cancer care. Entry into a research study is always a joint decision between the physician and the patient. By looking at the pros and cons of clinical trials and your other treatment choices, you are taking an active role in a decision that affects your life. If you are interested in participating in a research study, please ask your physician if there is a clinical trial appropriate for you. To contact IORA, please call (515) 244-7586.

Lymphedema Clinic - Lymphedema is an abnormal accumulation of fluid which causes swelling of a body part, most frequently in an arm or leg. Lymphedema can be caused by a malformation in the lymphatic system. In some cancer patients, it can occur as the result of a disease process or tissue damage (from surgery, radiation, or trauma). Damage to the lymphatic vessels or lymph nodes increase the likelihood of developing lymphedema. Lymphedema may occur years after the original damage and is often triggered by infection or injury. It affects an estimated two to three million Americans. There is a 30 percent incidence of lymphedema as a result of breast cancer treatment. Prevention of lymphedema requires individuals at risk to take special precautions and to be able to detect its onset. Lymphedema has no cure, but can be successfully managed through therapeutic intervention. Lymphedema is best treated with Complete Decongestive Therapy (CDT), a comprehensive treatment program. For more information, please call (515) 241-6839.

Child Life Specialists - Child life specialists, located at Blank Children’s Hospital, help children to find ways to cope with fear, anxiety and separation from family and friends. By using play, recreation and educational techniques, they enable children to better understand what is happening — reducing stress and increasing cooperation. They can also help children understand and face the fears of a parent being diagnosed with cancer and receiving treatments. Please call (515) 241-6276.

Social Worker - Staff are available to identify individual patient needs, such as facilitation of discharge planning, including transfers to home or other healthcare options. The social worker will provide counsel and support to patients and families and link them with the most appropriate community resources. A case manager can also facilitate and coordinate issues such as Medical and General Power of Attorney, Advanced Directives-Living Wills, Guardianship and Conservatorship. Additionally, he or she can assist patients, families, caregivers, and hospital personnel with decision making about ethical issues and initiate referrals to the bio-ethics committee as needed. Please call (515) 241-6105.

Dietitians - A clinical dietitian is on staff to regularly review the nutritional care of our patients. Responsibilities include completion of nutrition assessments, counseling and education on special diets, dealing with side effects of disease and treatments, and ways to improve nutritional status. Please call (515) 241-3310.

Oncology Pharmacists - An oncology pharmacist is available on the John Stoddard Adult Inpatient Oncology Unit to provide our patients and staff with drug information and education. Please call (515) 241-3466 during daytime hours.

Chaplains - Chaplains are available 24 hours a day to address the spiritual needs of our patients. Regular religious services are held in the hospital chapel and available on closed circuit television. Special spiritual ministries offered include baptism and communion upon request. Our chaplains will work with the patient’s pastor, priest, rabbi, etc. as needed. Please call (515) 241-6411.

Psychologist - A clinical psychologist can provide counseling for cancer patients and/or family members to assist in the emotional challenge of dealing with cancer. Please call (515) 241-4280.

UnityPoint at Home – UnityPoint at Home, formerly Iowa Health Home Care, was formed in 1998 to provide patients and families with high-quality, compassionate and cost-effective home care needs. Call us at (515) 557-3100 to make a referral, set up a service or simply learn more about what we have to offer.

Taylor House Hospice - Hospice is a specialized way of caring for persons of any age with advanced stages of any non-curable illness. Hospice does not mean "giving up." It shifts the focus from finding a cure to providing comfort. It can be provided in a patient’s home or at Taylor House. Taylor House was built to provide care and comfort to terminally ill patients and their families who seek an alternative to care in hospitals or nursing homes. Taylor House is staffed 24-hours a day, seven days a week, with at least one nurse on duty at all times. There are also certified nursing assistants and volunteers. For more information, please call (515) 557-3111. For more information on all of the John Stoddard Cancer Center services, please visit our website at www.johnstoddardcancer.org.
ONCOLOGY WEBSITES

John Stoddard Cancer Center (www.johnstoddardcancer.org)
American Cancer Society (www.cancer.org/)
American Institute for Cancer Research (www.aicr.org/)
American Medical Association (www.ama-assn.org/)
American Society of Clinical Oncology (www.cancer.net)
American Society of Lymphology (www.lymphology.com)
Association of Community Cancer Centers (www.accc-cancer.org/)
CancerCare (www.cancercare.org)
CancerFacts (www.cancerfacts.com/)
Eastern Cooperative Oncology Group (ECOG) (ecog.dfci.harvard.edu)
healthfinder ™ (www.healthfinder.gov/)
Journal of Clinical Oncology (www.jco.org/)
Lymphedema International Network (www.lymphedema.com)
MAMM (www.mamm.com/)
National Cancer Institute (www.cancer.gov/)
National Lymphedema Network (NLN) (www.lymphnet.org)
North Central Cancer Treatment Group (NCCTG) (ncctg.mayo.edu/)
OncoLink (www.oncolink.upenn.edu/)
People Living With Cancer (www.oncology.com)
Radiation Therapy Oncology Group (www.rtog.org/)
Radiological Society of North America, Inc. (RSNA) (www.rsna.org/)
Susan G. Komen Breast Cancer Foundation (www.komen.org/)
QUESTIONS TO ASK YOUR DOCTOR
Source: Iowa American Cancer Society Office

WAITING FOR RESULTS
When is the test going to be back? I want to know immediately. I don’t want to have to wait.

CHOOSING A DOCTOR
• What are the doctor’s office hours?
• Does he or she take Saturday or evening appointments?
• How soon can I make an appointment?
• Is the doctor normally on time for appointments?
• What is the doctor’s fee schedule?
• Is the doctor available for telephone consultation after the first appointment?
• What kind of medical insurance does this doctor accept?
• Will this doctor be available throughout my treatment?
• Does this doctor seem warm and personable or cold and remote?

AFTER DIAGNOSIS
• What kind of cancer do I have and where is it located?
• Has it spread to other parts of my body?
• What stage is my cancer?
• What are these tests that we are doing and what will they tell me about my cancer?
• Is there any doubt about my diagnosis?
• How many cancers of my type do you see a year?

TESTS
• How accurate are the tests?
• How soon will the results be back, and how will I be notified?
• Will more tests be required?
• Did the pathologist check his/her findings with others?

PHYSICIAN
• Did you consult with anyone before you made the diagnosis? If so, with whom?
• What will their role be?
• What procedure do you recommend?

TREATMENT
• What is the standard treatment for this type of cancer?
• What are my chances with this treatment?
• What are the potential risks and benefits?
• How many patients usually respond to this type of treatment?
• What are the side effects?
• Do I need someone to accompany me to treatments?
• Are there alternative ways to proceed?
• What will be the cost of treatments?
• Will I be able to return to my normal life after treatment?
• What might happen if I decide not to undergo treatment?
• How soon must I decide about my treatment?
• How long does this treatment last?
• How will I receive my treatment?
SURGERY

- In simple terms, what is the purpose of the surgery?
- How much surgery is being done? Why? (For example, if you are a breast cancer patient, how much breast, if any, will be removed? Of the surrounding tissue? Of the under arm lymph nodes?)
- If exploratory surgery is being planned, why? If exploration reveals a tumor, will it be taken out at the same time?
- What are my chances of being cured by this surgery? Of seeing my condition improve?
- What would I risk by not having the surgery?
- Could I die from the surgery or its possible complications? How high is the risk? What are the possible side effects of surgery, including pain of the surgery and the postoperative healing process?
- Are other treatments available?
- Is the surgery likely to leave me disabled or disfigured? If so, will rehabilitation or reconstruction be possible?
- How long will I be in the hospital? How long will it take me to recover completely?
- Will I need further treatment after surgery?
- How much will the surgery cost?

CHEMOTHERAPY

- Why do I need chemotherapy?
- Are there other types of treatment for my cancer?
- How successful is the chemotherapy likely to be?
- How successful are other treatments likely to be?
- What are the benefits of each option?
- What medications will I be taking? How and where will they be given?
- How long will a treatment session last?
- How long will I have to have chemotherapy?
- What are the possible long-and short-term side effects? How quickly are they likely to appear and disappear?
- Will there be restrictions on my diet, work or other activities?
- What will therapy cost?

RADIATION

- Why do I need radiation?
- Are there other types of treatment for my cancer?
- How successful is the radiation likely to be?
- How successful are other treatments likely to be?
- What are the risks and benefits of each treatment?
- Which parts of my body will be treated? Will the tissue surrounding the tumor be affected?
- How long will the course of treatment last and how long will each treatment session last?
- What are the possible long-and short-term side effects?
- Should I take any special precautions during and after treatment? Should I take special care of my skin?
- What will the treatment cost?
SUPPORT
• Is there access to a social worker?
• Is there access to a dietitian if I have nutritional concerns or difficulties?
• Do I need to be on a special diet?
• Do I need to change my lifestyle?
• Can I have sex?
• What type of precautions do I need to take?
• Who do I call if I have an emergency?
• What are the phone numbers I should have in order to reach you? Nurse? Hospital?

CLINICAL TRIALS
• What is the purpose of the study?
• What kind of test and treatment are involved?
• What is likely to happen to me with this treatment? Without it?
• Are there other treatments? What are their advantages and disadvantages?
• How long will the study last?
• Will it affect my daily life? How?
• Will the treatment have side effects? What are they?
• Will I have to be hospitalized? How often? For how long?
• Will it cost me anything to participate?
• If I am harmed from the study, will I receive any treatment?
• Does the study include long-term follow-up care?
POSSIBLE POST-SURGICAL PROBLEMS

INFECTION
Patients who have undergone Axillary Lymph Node Dissection (ALND) have an increased risk for infection due to the removal of lymph nodes and interruption of the lymph vessels. The surgical site must be carefully monitored in addition to the arm and surrounding trunk. In addition to proper hygiene and preventative techniques, education in the signs and symptoms of infection (also referred to as cellulitis or lymphangitis) can reduce the likelihood of an increase in swelling, poor healing, skin breakdown, and recurrence. Consult physician immediately if any of these signs or symptoms is noticed.

Signs and Symptoms
Watch the involved arm and surrounding trunk for:
- A rash, red blotches and itching
- Discoloration
- Increased swelling
- Increased temperature
- Heavy sensation in the arm
- Decreased movement in arm
- Pain radiating in the axilla
- Malaise, chills, high fever

Treatment
Most patients will benefit from:
- Oral antibiotics
- Rest
- Elevation of the involved arm
- Increase fluid intake
- Watch for changes in the arm and surrounding trunk
- Check temperature frequently

Prevention of infections is essential to limit further complications to the lymphatic system.

MASTITIS
Mastitis is a breast inflammation usually caused by infection. It normally starts as a painful area in the breast. You may notice redness and warmth of the area in question and have fever, chills, or body aches. If you develop these symptoms, notify your physician.

SEROMA FORMATION
A seroma is an accumulation of fluid in the location of surgery. This fluid is mostly absorbed by the body, but may need occasional drainage with the needle and syringe (aspiration).

HEMATOMAS
Hematomas are collections of blood pooling in the tissue at the surgical site. Notify your doctor immediately should you experience sudden swelling of the breast with increased, sudden, severe pain.
SENSATION CHANGES
After surgery involving removal of axillary lymph nodes, the incision and surrounding area will have an altered sensation (pain, numbness, tingling). Incisonal pain is caused by the direct surgical trauma to the skin and underlying tissue. It may be increased by drains, dressings, and tape. Immediate post-op swelling may also increase incisional pain. This type of pain is located at the incision and drain sites and the immediately surrounding tissue. This area may also feel very tight and experience a pulling sensation with movement. Muscle tightness and soreness may be evident as well. Incisional pain is temporary. It begins improving as the drains, sutures or staples are removed and continues to improve as healing occurs.

Neurological pain is the result of sensory nerves being stretched, injured or cut during surgery. The most common sensation is numbness, tingling or prickling in the under arm, side chest wall, and inner and backside of upper arm. Some patients may also experience an aching or burning sensation. If the breast was removed, phantom breast pain could be a factor. These nerve sensations are usually temporary and improve in a few months. If the nerve was cut, the sensation will decrease but may be permanent. This should not affect the use of your arm.

Gentle stretching exercises will improve these sensory changes and will allow for a gradual return to normal functional activities. Remember to avoid incisional stretch pain or any sharp pain while performing exercises. As the incision heals, the sensation and flexibility of the incision and surrounding tissue will continue to improve and may be enhanced by gentle scar massage. A therapist can teach this technique.

THE LYMPH SYSTEM AFTER AXILLARY LYMPH NODE DISSECTION (ALND) SURGERY and SENTINEL LYMPH NODE BIOPSY
An axillary lymph node dissection surgery routinely involves the removal of lymph nodes from the (axilla) armpit. These lymph nodes and associated lymph vessels play an important role in the body’s immune system. Normally there are 25 to 45 lymph nodes in each axillary region. These axillary lymph nodes help drain the arm, upper back and chest on that side of the body. The lymph vessels pick up large proteins, toxins, wastes, bacteria, any cancer cells, and about 10-20% of the fluid that circulates throughout the body. Once this fluid enters the lymph vessel it is known as lymph fluid. Lymph fluid is sticky and tinged slightly yellow. The lymph vessels drain this lymph fluid into the axillary lymph nodes. The lymph nodes have macrophage cells that break up the proteins and waste. They also make lymphocytes which help fight infection, destroying bacteria and toxins.

Sentinel lymph node biopsy is now the standard technique for finding and measuring the spread of cancer to the axillary lymph nodes. The sentinel nodes are the first nodes through which lymphatic fluid flows from a tumor, and can be called the “gatekeepers” to the rest of the lymph nodes. With the sentinel node biopsy procedure, doctors expect that fewer women will develop lymphedema.

The removal or impairment of these lymph nodes through surgery or radiation, puts you at risk for lymphedema. Lymphedema is an abnormal accumulation of lymphatic fluid (protein and water) that causes swelling of a body part, most frequently the arm, breast, or chest. The body will try to compensate for the missing lymph nodes by finding other ways to drain your arm, chest, and upper back. It does this by using the lymph nodes under your collar bone, your neck, and the other armpit. The remaining lymph nodes will work harder to take over for the missing ones. When this alternate route of lymphatic drainage is ineffective or overloaded, the lymph fluid begins to accumulate in the tissues and results in lymphedema.
LYMPHEDEMA PRECAUTIONS
The surgical procedure for Axillary Lymph Node Dissection (ALND) results in the removal of lymph nodes. This surgical removal of lymph nodes and vessels may cause a swelling called Lymphedema. This swelling is due to accumulation of lymph fluid caused by impaired lymph flow and removal of lymph nodes from the arm and/or breast region. The risk factors can be minimized by preventing infection and avoiding anything that restricts lymph flow. Immediately following surgery it is essential to decrease the risk of infection, prevent injury, and avoid increased pressure (known as the Three I’s) to the involved arm and breast tissue by following these precautions on the involved side:

The Three I’s
• Injury – Avoid injury to the affected arm, such as muscle strain, burns, and overheating. This reduces the likelihood of inflammation.
• Infection – Avoid any break in the skin which can be an entry point for infection. Check skin on a daily basis for cuts, burns or bites.
• Increased Pressure – Avoid anything which increases pressure or causes constriction on affected arm. This may increase fluid and swelling as well as reduce lymph flow.

Special guidelines during medical appointments for the involved arm are:
1) No IV’s
2) No Blood Pressures
3) No Injections or Blood Draws

Lymphedema alert wristbands are available to reinforce these guidelines. It should be worn on the involved arm during hospitalization. It is reusable and can be worn to alert other healthcare providers during medical or dental appointments. Another recommendation is to store it in a billfold or purse with medical identification in the case of an emergency. The band should be labeled with an R or L to indicate which arm is at risk. Signs can also be posted during hospitalization to inform medical personnel during procedures.

Physical recovery requires continued monitoring of your health and risk factors for lymphedema. The first line of defense against lymphedema is prevention. Practicing the Three I’s after axillary lymph node surgery is necessary to facilitate flow of lymph fluid from the arm. Awareness and self-monitoring of these prevention guidelines should be for a lifetime.
DRESSING AND DRAIN MANAGEMENT

These are general instructions. If your doctor gives you specific instructions that differ from these, you should follow the doctor’s instructions. Feel free to discuss any questions with your nurse.

Incision Care

♦ Observe the incision carefully to familiarize yourself with the scar area. This allows you to monitor the incision for changes after you return home. Notice the color, odor, and amount of drainage on dressing.

♦ Keep the incision dressing clean and dry to decrease risk for infection, prevent skin irritation and skin breakdown.

♦ Wash your incision gently with soap and water. Dry well. You may shower or tub bathe if you have no drains in place. If you have steri strips (small strips of tape) across your incision, they may be removed as each one loosens (3-5 days). Do not attempt to remove stitches or staples. A doctor or nurse should do this. Do not apply powders, deodorant, lotions or any perfumed items to your incision or under your arm until incision is healed.
   - Gather all dressing supplies.
   - Wash hands well.
   - Wipe off any old blood or tape residue starting near the incision and wiping away from it.
   - Place clean dressing on area.
   - May cover steri strips with soft dressing or covering to prevent irritation or rubbing by clothing.
   - May want to wear a soft tee shirt or cotton sports bra to minimize rubbing by clothing.

♦ Monitor areas for changes that might indicate infection. Normal drainage should be a blood-tinged discharge with no odor.

♦ Call your doctor if:
   - There is an increase in swelling or tenderness at the incisional site.
   - Have an increased amount of drainage on the dressings.
   - You notice a foul smell from your incision.
   - There is redness around the incision.
   - You have a temperature over 101 degrees F for over 4 hours.

Jackson Pratt Drain

♦ During surgery, a drainage catheter called a Jackson Pratt (JP) Drain might be inserted under the skin surface of your incision. It is possible that you may go home with this drain in place. This drain collects fluid to reduce swelling, pain, and pressure on the incision.

The tubing is stitched to the skin and ends in a soft plastic bulb that collects the fluid, which is a mixture of blood cells and lymphatic fluid. The drainage is initially a dark red, gradually becomes pink tinged and finally a yellow straw color. As the small lymph and blood vessels seal themselves off, the drainage slowly stops. The amount of fluid and the time it drains varies among patients. The physician removes the drain when it is no longer needed.

♦ Do not let drains hang loosely. This may pull on the incision and cause pain and scarring. Always secure drain to clothing and empty when it becomes heavy.
JACKSON PRATT (JP) DRAIN CARE INSTRUCTIONS

These are general instructions. If your doctor gives you specific instructions that differ from these, you should follow the doctor’s instructions. Feel free to discuss any questions with your nurse.

SUPPLIES
- Measuring cup
- Record sheet
- 4x4 gauze and tape

DRESSING CHANGE
To be done daily and as needed.
- Wash hands well.
- Take off old dressing.
- Look at the skin around the drain site for signs of infection (redness, warmth, and pus-like drainage).
- Place new 4x4 gauze around the drain site.
- Tape the gauze to skin to hold the dressing in place.

HOW TO EMPTY AND RECHARGE JP DRAIN
Empty the fluid collected in the drain bulb 2-3 times a day and as needed.
- Wash hands well.
- Point the tip of the bulb away from you and remove the stopper. The bulb will fill with air.
- Turn the bulb upside down over a measuring cup, and squeeze the contents into the container.
- Squeeze the bulb to force the air out, and then replace the stopper. The bulb should now be compressed and look flat.
- Measure the amount of drainage and write this on the record sheet. Discard the fluid down the toilet or drain.
- Reposition the tubing and bulb so there are no kinks and it does not pull on the incision.
- Strip the drain each time it is emptied and as needed. (See below)

PREVENT DRAIN OCCLUSION
- With the drain tubing straight and without tension on the incision, “strip” the tubing.
- With one hand, firmly hold the tubing next to your skin with your thumb and index finger.
- Put the thumb and index finger of your other hand on the tube next to the first hand. Pinch your fingers together, and then pull them along the tubing toward the bulb. This helps to open the drain and push fluid into the bulb.

NOTIFY THE DOCTOR
- If the drainage color becomes bright red.
- If the drainage changes from thin and clear to pus.
- If the bulb does not stay flat after emptying and replacing the stopper.
- Redness and/or warmth around the insertion site or incision.
- Fever of 101 degrees or more
- There is a drastic decrease in the drain output with an increase in pain.
- If you have followed the instructions above and the drain still will not work properly.
JP DRAINAGE AMOUNT RECORD SHEET
Please bring this sheet with you to your doctor's appointment.

<table>
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<tr>
<th>Date and Time</th>
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Recovery
Recommendations
Recovery Recommendations

ELEVATION
♦ Elevation of the affected arm is necessary to reduce pressure and may facilitate venous and lymphatic drainage. This can reduce the tendency to become swollen, prevent fluid accumulation, and decrease pain.
♦ It is normal for the arm to swell slightly after surgery and it may be uncomfortable to raise the arm. This swelling should subside within 6 weeks, although it may require simple interventions such as arm elevation. It may also persist or be aggravated if chemotherapy and/or radiation follow surgery.
♦ If swelling of affected arm is greater than 2 cm or persists longer than 3 months, these may be early signs that lymphedema is present. (See Lymphedema Education section.)
♦ The goal of elevation is to avoid prolonged dependent positioning of affected arm.
♦ Technique: The angle of the arm should be above the heart level while sitting or lying.
  - Position the affected arm slightly away from the body and supported on pillows so hand and fingers are higher than wrist and elbow is higher than shoulder. The arm should be relaxed and held as straight as comfortable.
  - Avoid laying on affected arm and trunk.
  - Elevate for 45 minutes two to three times a day and anytime at rest.

DEEP BREATHING
♦ Deep breathing and coughing will improve oxygen flow, increase lung expansion, decrease discomfort, promote relaxation, enhance lymphatic drainage, and help overcome the effects of surgical anesthesia.
♦ Headache, nausea, as well as throat soreness after surgery may be present due to the tube inserted during surgery. These symptoms often cause patients to take shallow breaths, which decreases oxygen flow, relaxation, and chest expansion. Deep breathing, if done properly, increases chest wall expansion of the lower chest and rib cage.
♦ Technique: May perform in lying, sitting, and standing positions.
  - Inhale deeply through the nose, letting the chest expand upward and outward as the abdomen swells out.
  - Exhale slowly through the mouth as the abdomen is flattened.
  - Gradually increase the depth of breathing to avoid incisinal stretch pain and to avoid sudden movements that may aggravate sore tissues.
  - Perform 10 repetitions every 2 hours while awake for the first 24-48 hours after surgery.
  - Continued deep breathing on a daily basis will also help recovery.
POSTURE

Proper posture is important to achieve a return to normal function for those having axillary lymph node surgery. Surgical patients often adopt protective postures due to pain, discomfort, and tightness. Splinting and shoulder guarding due to pain can result in poor posture and movement. Improper posture can interfere with proper joint mobility and strength as well as lymphatic drainage. Maintaining proper body alignment promotes optimal lymphatic flow, joint mobility, reverses protective guarding positions, enhances deep breathing, prevents muscle weakness, and improves breathing capacity.

Awareness is the first key to better posture. Practice is the next step.
Proper upright posture consists of sitting and standing with:

1. Head held erect with chin tucked
2. Shoulders back and level
3. Chest held moderately elevated and upper back erect
4. Abdominal muscles tightened and flat
5. Lower back with a slight forward curve
6. Hips level and knees forward

Imagine that the top of your head is suspended from a string to create a straight vertical alignment for your body from the top of your head, through your body’s center, to the bottom of your feet. Head, shoulders, knees, and hips are level.

Make proper posture a good habit.
EXERCISES

♦ Patients may have difficulty lifting their arm due to muscle tightness and soreness around the shoulder due to surgery.
♦ Gentle active exercise can improve circulation and decrease post-operative swelling and stiffness by keeping the blood and lymphatic fluid moving and overcoming tissue restriction.
♦ Restoring full movement of the affected side helps to resume daily activities comfortably, prevent loss of shoulder range of motion and to improve muscle strength.
♦ Techniques:
  - All movements should be relaxed, avoid any undo muscle tension.
  - Avoid pain, incisional stretch, and tension on the drains.
  - Hold each exercise for ten counts. Perform five repetitions, twice daily, then slowly increase to ten repetitions.
♦ It is recommended that patients be referred to the Lymphedema Clinic at 2-3 weeks after surgery (once drains and sutures have been removed) for additional rehabilitation.

Begin these the day after surgery.

Neck Stretch – Rotation
Slowly turn head to look over right shoulder. Hold.
Slowly turn back to look over left shoulder. Hold.
Return to starting position

Neck Stretch - Lateral Flexion
Tilt ear toward right shoulder. Hold. Tilt ear to left shoulder. Hold. Return to starting position.

Neck Stretch – Extension
Gently tip head back to look up to the ceiling. Hold.
Return to starting position.
Shoulder Shrugs
Shrug both shoulders up and breathe in. Breathe slowly out as you lower your shoulders.

Scapular Retraction
Sit with arms and shoulders relaxed. Squeeze shoulder blades tightly together, keeping elbows relaxed in lap. Hold ten seconds.

Shoulder Touches
Touch hand to opposite shoulder. Slowly reach arm out to side at shoulder height. Lower arm to side.

Shoulder Extension
Bring arms straight behind you as far as possible while keeping body upright. Hold ten counts. Return to starting position.
**Shoulder Internal Rotation**
Bend affected arm up behind back as far as possible. May assist arm motion by clasping affected wrist with the other hand and gently pushing upwards. Repeat with other arm.

![Diagram of Shoulder Internal Rotation](image)

**Shoulder External Rotation**
Reach behind head trying to touch shoulder blades. Bring elbow back gently. Repeat with other arm.

![Diagram of Shoulder External Rotation](image)

**Finger/Hand Pumping**
Gently squeeze fingers together making a fist. Slowly open hand and spread fingers apart. Then slowly press fingers together. May raise arm over your head as able while opening and closing hand.

![Diagram of Finger/Hand Pumping](image)
Elbow Flexion and Extension
Bend elbow so that finger tips touch shoulder.
Straighten elbow with palm up.

Forearm Supination and Pronation
Hold elbow at side at a right angle with wrist straight. Start with arm in hand-shaking position and slowly rotate palm down until a stretch is felt. Hold ten seconds. Relax. Then rotate palm up until a stretch is felt. Hold ten seconds. Relax.

Wrist Flexion and Extension
Actively bend wrist forward and backward as far as possible

Wrist Circles
Make a fist and rotate it in a circle.
Repeat in the other direction
Begin 8-10 days after surgery.

Reaching overhead should be limited the first 8-10 days after surgery. At this point the following two exercises need to be added to gently increase shoulder range of motion. Overhead shoulder activities may be gradually added as tolerated.

**Shoulder Flexion**
Bring arm straight out in front of body and raise as high as possible, keeping elbow straight and thumb pointing up. Lower arm to side. Repeat with other arm.

**Shoulder Abduction**
Bring arm straight out to side and raise as high as possible, keeping elbows straight and thumb pointing up. Lower arm to side. Repeat with other arm.
ACTIVITY GUIDELINES

Returning to your previous lifestyle and activities should be done in a gradual and safe manner. How to progress these activities does not have to be a guessing game which can result in pain, stiffness, poor posture, and swelling if overdone. Activities can be grouped into categories based on time lapsed since surgery and patient tolerance. General activity considerations are provided to retrain the involved arm and to gradually improve tolerance to activity.

♦ Limit arm motion until the drain is removed

♦ Use other arm to assist if involved arm is weaker

♦ After the drain is removed, use the arm that you would normally use to perform activities

♦ Monitor pain, muscle stiffness, and arm tolerance to activity

Activities of Daily Living

➢ Discharge/after 1st 24 hours: light activities – equal to 1 pound (make-up, phone, bathe upper body, comb/brush hair, hair dryer, newspaper, TV remote control, lift glass or cup)
   1. Do not sleep on your stomach or sides. Sleep on your back. You may lie flat.
   2. Walking is a good form of exercise.
   3. You may go up stairs
   4. No lifting, running, jumping or jogging.
   5. Do not drive a car until your doctor allows you to do so.

➢ 1 week: medium activities – less than 3-5 pounds, (light cooking and dusting, laundry-fold and put away, hanging clothes in closet, make bed. May begin reaching overhead 8-10 days after surgery.)

➢ 1 month: medium/heavy activities – less than 5-10 pounds, (carrying a heavy purse, shopping, most routine activities)

➢ 2 months: heavy weight activities – less than 10-15 pounds, (whatever is comfortable to carry such as a bag or briefcase; shopping bag; yardwork, light sports, swimming

➢ Lifting precautions – These activities need to be avoided or modified until arm tolerance improves:
   -Lifting children
   -Moving furniture
   -Carrying luggage
   -Vigorous vacuuming

➢ This is a general activity guideline. Some individuals may progress a little slower, while some may be able to return to activities more quickly. This may be due to your activity level before surgery, the extent of surgery or complications, tolerance to pain, and support help after surgery. Remember to monitor your arm’s tolerance to activity and if an activity hurts, stop and check with your physician or therapist.
Activity Considerations

A. Protect Arm – protect against sunburn, minor injuries, and irritated or dry skin. If travelling by air, you may need to wear a compression sleeve and glove.

B. Gradual return to exercise/activity – All movements should be comfortable. Initially while performing stretches, a gentle, light stretch should be felt. These should be continued until full flexibility is reached without even a sensation of pulling, tightness, or stiffness in the arm and chest. Be sure not to strain, hold breath, or force any movements. Strengthening exercises can be progressed to minimal effort with no straining. These are performed until done with ease and the strength is equal to that of the other arm.

C. Gradually and gently restore normal function of your arm and chest – Do not cradle or favor the involved arm. Move it normally again with the help of flexibility and strengthening exercises. Always be aware of proper posture during exercise and activity.

D. Assess your arm’s tolerance to progression of activities – gently squeeze forearm after an activity to make sure arm did not get swollen or harder than normal. If swelling or hardness increases, cut back on your repetitions, time spent doing this activity or resistance/weight used. Use arm as a gauge to determine if activity is tolerated. If swelling persists consult with physician about a referral to a lymphedema therapist.

Please refer to the Lymphedema Education section for additional information on activities and preventing lymphedema.
FATIGUE/REST GUIDELINES

Fatigue may be a side effect after surgery. Fatigue is when people have less energy to do the things they normally do or want to do. A person can experience temporary fatigue after surgery. With cancer, the fatigue may be last longer and be more intense. Cancer-treatment related fatigue can appear suddenly and can be overwhelming. Rest does not always relieve it. It can last after treatment ends and may persist for several months. Common causes of fatigue may be due to medications, depression, medical causes, too much or too little rest, or excessive stimulation or activity. Learn to recognize these symptoms and how to manage fatigue until you recover from surgery.

What to Look For
- Feeling like you have no energy
- Feeling like you have to sleep more than usual
- Not wanting to do normal activities
- Decreased attention to personal appearance
- Feeling tired, even after sleeping
- Trouble concentrating

What to Do
- Prioritize activities to make sure you have energy for important things
- Schedule activities throughout the day rather than all at once
- Plan rest periods
- Get enough rest and sleep but don’t overdo (sometimes too much rest can make you feel tired and make it more difficult to sleep)
- Eat nutritious foods and drink plenty of liquids
- Let others help you with meals, housework, and errands
- Reward yourself whenever possible with pleasant activities, such as listening to music, enjoying nature, taking a walk or visiting with family and friends.
- Discuss with your physician.

ENERGY CONSERVATION AND PACING

Recovery following surgery should be focused on gradually returning to normal functional activities and restoring normal range of motion and strength of the involved arm. The above activity guidelines suggest how to progress activities, but finding ways to simplify activities and conserve energy can also enhance the recovery process. The recovery time may vary among individuals but it can be managed. Before beginning daily activities, consider the following guidelines:

1. Set priorities. Determine what you want to accomplish in order of importance.
2. Plan ahead, but be flexible.
3. Recognize your energy limits. Be realistic and don’t over do a good day.
4. Take frequent rest breaks as needed. Divide each task into steps and take a break between steps.
LYMPHEDEMA EDUCATION

What is Lymphedema?

Lymphedema (swelling) is an accumulation of lymphatic fluid (protein and water) that causes swelling of a body part, most frequently in an arm or legs. Edema occurs when venous or lymphatic vessels or both are impaired. When the impairment is so extreme that the lymph fluid exceeds the lymphatic flow capacity, an unhealthy amount of protein fluid collects in the tissues of the extremity.

If untreated, this fluid causes tissue channels to increase in size and number, reduces oxygen flow throughout the system, impairs wound healing and creates a bacteria-prone condition that can result in infection. Chronic inflammation from this accumulation of fluid eventually results in fibrosis, or hardening, of the soft tissue.

The lymphatic system is a drainage pathway for tissue fluid that is outside the bloodstream. It is also an integral part of your body’s immune system. Lymph fluid circulates very slowly throughout your system while suspending immune lymphocytes, which are specialized white blood cells to fight diseases.

Normally, a small amount of plasma, the liquid part of the blood, trickles out of the bloodstream into tissues along with a few white blood cells (lymphocytes). The leaked fluid and cells re-circulate back into the bloodstream through intervening lymph nodes via thin, almost transparent lymph vessels. Lymph vessels contract and actively pump lymph fluid forward and, once the fluid is pumped, valves keep it from backing up. This is how a healthy system functions.

Interference with this lymph flow system (for example, after excision of axillary lymph nodes and attached lymphatics or obliteration by radiotherapy) reduces the capacity for drainage of lymph. Over time, swelling in the affected limb may appear. Because of this abnormal state, an unusual amount of fat and scar-like material collects, giving the arm or leg a firm, thick texture. This hardening of the underlying soft tissue and overall bulkiness contributes to the sensation of heaviness, tightness, and restricted motion. Because immunity is locally impaired, damage to axillary lymph nodes may cause the swollen arm to become highly susceptible to infection, which can further damage the remaining lymphatic channels.

What Is the Cause of Lymphedema?

Secondary Lymphedema occurs after surgical removal of lymph node(s), scarring of lymph vessels from radiation, trauma, infection, injury, chronic venous insufficiency and filariasis (parasite). Secondary lymphedema affects an estimated two to three million American. There is a 15 to 25 percent incidence of secondary lymphedema as a result of breast cancer treatments, such as surgery and radiation.

What are the Symptoms?

Lymphedema usually begins with swelling in the arm or hand and the chest area on the involved side. At first, only tightness or stiffness in the extremity may appear. If persistent swelling in the extremity or chest is noticed, it is very important to seek medical advice. If the problem is diagnosed and treatment begins early, the chance for improving the condition is much greater than if the swelling is ignored or goes untreated. When it is not managed, the limb becomes swollen (edematous) and the skin loses elasticity and eventually hardens (fibrosis). Once again, untreated lymphedema leads to infection and, possibly, irreversible complications.
Impact on the Lymphedema Patient

Psychosocial reactions of embarrassment, depression and withdrawal may occur; this is common. The lymphedema patient may experience:

• Loss of familiar body image; disfigurements.
• Feeling of heaviness and limitation of motion and function.
• Cosmetic problem, difficulty finding properly fitting apparel.
• Repeated episodes of infection.
• Altered lifestyle to prevent exacerbation of swelling or infection.
• Increased anxiety and depression.
• Loss of self-esteem.

Who Is At Risk?

You are at risk if you have had removal of lymph nodes and/or radiation to the lymph nodes. The involved area would be the arm or chest on the side where the axillary (armpit) lymph nodes have been removed and/or radiated.

Secondary lymphedema may occur immediately or years after the original surgery or radiation treatments. Injury or infection can also trigger lymphedema. The risk for lymphedema can be minimized by complete rehabilitation including skin care, exercise and education. Education is focused on the prevention of infection and the avoidance of anything that restricts lymph flow. With proper education and care, lymphedema can be avoided or, if it develops, kept under control.

Can Lymphedema Be Cured?

With early intervention and proper treatment, the condition can be controlled, allowing the individual to lead a full and normal life. Techniques for self-management and maintenance of swelling reduction and minimizing lymphedema complications are essential factors in control.

Lymphedema has no cure but can be successfully managed through therapeutic intervention.

What Next?

Lymphedema can be a serious condition that should not be ignored. With proper education, preventative measures and appropriate therapy, lymphedema can be controlled. If you have any symptoms or concerns about lymphedema, please contact your doctor. The Lymphedema Clinic at the John Stoddard Cancer Center is dedicated to providing and promoting lymphedema services and resources for patients and their families. The Lymphedema Clinic is here to promote education and awareness. For further information, contact the Lymphedema Clinic at (515) 241-6839.
I. Skin Care - Avoid trauma / injury to reduce infection risk

• Keep extremity clean and dry.
• Apply moisturizer daily to prevent chapping/chafing of skin.
• Attention to nail care; do not cut cuticles.
• Protect exposed skin with sunscreen and insect repellent.
• Use care with razors to avoid nicks and skin irritation.
• If possible, avoid punctures such as injections and blood draws.
• Wear gloves while doing activities that may cause skin injury (e.g. washing dishes, gardening, working with tools, using chemicals such as detergent).
• If scratches/punctures to skin occur, wash with soap and water, apply antibiotics, and observe for signs of infection (i.e. redness).
• If a rash, itching, redness, pain, increased skin temperature, increased swelling, fever or flu-like symptoms occur, contact your physician immediately for early treatment of possible infection.

II. Activity / Lifestyle

• Gradually build up the duration and intensity of any activity or exercise.
• Take frequent rest periods during activity to allow for limb recovery.
• Monitor the extremity during and after activity for any change in size, shape, tissue, texture, soreness, heaviness or firmness.
• Maintain optimal weight. Obesity is known to be a major lymphedema risk factor.

III. Avoid Limb Constriction

• If possible, avoid having blood pressure taken on the at-risk extremity, especially repetitive pumping.
• Wear non-constrictive jewelry and clothing.
• Avoid carrying a heavy bag or purse over the at-risk or lymphedematous extremity.

IV. Compression Garments

• Should be well-fitting
• Support the at-risk limb with a compression garment for strenuous activity (i.e. weight lifting, prolonged standing, and running) except in patients with open wounds or with poor circulation in the at-risk limb.
• Patients with lymphedema should consider wearing a well-fitting compression garment for air travel. The NLN cannot specifically recommend compression garments for prophylaxis in at-risk patients.
V. Extremes of Temperature

- Individuals should use common sense and proceed cautiously when using heat therapy. Observe if there is swelling in the at-risk limb or increased swelling in the lymphedematous limb and cease use of heat such as a hot tub or sauna.
- Avoid exposure to extreme cold, which can be associated with rebound swelling, or chapping of skin.
- Avoid prolonged (greater than 15 minutes) exposure to heat, particularly hot tubs and saunas.

VI. Additional Practices Specific to Lower Extremity Lymphedema

- Avoid prolonged standing, sitting or crossing legs to reduce stagnation of fluid in the dependent extremity.
- Wear proper, well-fitting footwear and hosiery.
- Support the at-risk limb with a compression garment for strenuous activity except in patients with open wounds or with poor circulation in the at-risk limb.

NOTE: Given that there is little evidence-based literature regarding many of these practices, the majority of the recommendations must at this time are based on the knowledge of pathophysiology and decades of clinical experience by experts in the field.
DEFINITION: Lymphedema (swelling) is an accumulation of fluid in the tissues due to an insufficient lymphatic system. Damage to lymphatic vessels and/or nodes interferes with the lymphatic system's ability to remove fluid from the tissues, resulting in swelling.

What are my specific risk factors which may contribute to the development of lymphedema?
Individuals who have undergone cancer surgery with the removal of axillary lymph nodes are at risk for developing lymphedema. Also, individuals who have had radiation to the axillary lymph nodes and surrounding tissue are at risk for developing lymphedema.

How do I know if I am developing lymphedema? What does it feel like?
The arm and the trunk, including the breast and shoulder areas, will begin to demonstrate changes from their normal condition. Compare both sides, looking for differences such as those listed below:

Common symptoms
- Visible swelling
- Puffiness
- Fullness
- Tightness
- Heavy sensation
- Pressure sensation
- Discomfort or aching
- Fatigue
- Bursting sensation
- Heat or burning sensation
- Clothes/shoes/jewelry fitting snug

What happens if the lymphedema goes untreated?
If your swelling is left untreated or poorly managed, progressive tissue changes can occur. The tissues, once soft and thick, will become hard and fibrotic and may lead to more chronic skin changes such as those listed below:

Progressive symptoms
- Soft tissues become hard and fibrotic
- Dry skin
- Skin discoloration (red / brownish)
- Clear liquid leaking from skin
- Blisters/Wounds
- Impaired sensation

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(515) 241-6839
Lymphedema Clinic

Lymphedema is an abnormal accumulation of fluid which causes swelling of a body part, most frequently in an arm or leg. Lymphedema can be caused by a malformation in the lymphatic system. In some cancer patients, it can occur as the result of a disease process or tissue damage (from surgery, radiation, or trauma). Damage to or destruction of the lymphatic vessels or lymph nodes increase the likelihood of developing lymphedema.

Lymphedema may occur years after the original damage and is often triggered by infection or injury. It affects an estimated two to three million Americans. There is a 30 percent incidence of secondary lymphedema as a result of breast cancer treatment.

Prevention of lymphedema requires individuals at risk to take special precautions and to be able to detect its onset. Lymphedema has no cure, but can be successfully managed through therapeutic intervention.

Lymphedema is best treated with Complete Decongestive Therapy (CDT), a comprehensive treatment program which includes:

- Manual Lymphatic Drainage (MLD)
- Compression bandaging
- Compression garments
- Lymphedema exercises
- Meticulous skin and nail care
- Education and prevention for self-management

The goals of CDT are:

- Consistent reduction of swelling and fibrous tissue
- Prevention of lymph fluid re-accumulation
- Improved movement and function
- Prevention and elimination of infections
- Self-esteem enhancement

A preventative treatment program is available for post-surgical patients at risk for lymphedema. This program includes:

- Range of motion exercises
- Stretching and strengthening exercises
- Posture training
- Education and prevention

This treatment program is provided by a physical therapist or an occupational therapist that is a Certified Lymphedema Therapist MLD/CDP and also nationally certified by the Lymphology Association of North America (LANA). A physician’s referral for this service is required. For more information on the Lymphedema Clinic, please call (515) 241-6839.
NO BLOOD TESTS, BLOOD PRESSURES

NO I.V.’s OR INJECTIONS INTO ___ ARM

LYMPHEDEMA CLINIC
John Stoddard Cancer Center
1221 Pleasant Street, Suite 450
Des Moines, IA 50309
(515) 241-6839
This section applies only if you have had Breast Surgery
Physical recovery requires continued monitoring of your health and the continuation of breast self-exam after surgery. This will need to continue monthly on the remaining breast tissue and chest area. After breast surgery it will be important to learn what is normal for you. The involved side will feel different and your surgeon can help you distinguish these changes. Incision scars and drain scars may have areas that feel firm, which is caused by scar tissue. Also check the area above the collarbone and the armpit. If radiation therapy is to follow surgery, the breast and/or remaining tissue will undergo additional changes. Discuss with your physician changes you may expect.

Schedule for monthly breast self-exams:
When to start:
- Lumpectomy patients should begin when the incision has healed completely or upon completion of radiation therapy. The remaining breast tissue and the scar area should be examined.
- Mastectomy patients should begin examination of the surgical site approximately two to three months after surgery. Examine the scar and surrounding area.
- Reconstructive surgery patients should examine the entire reconstruction area when the incision has healed completely, approximately two to three months after surgery.

When to perform:
- Menstruating women should check their breasts 7-10 days after menstrual period begins.
- Post-menopausal women or those who don’t have regular menstrual periods (may be due to receiving cancer treatment), should do it on the same day every month.

Technique for Monthly Breast Self-Exam:
In the Shower:
- Raise one arm.
- With fingers flat, touch every part of each breast, gently feeling for a lump or thickening.

Before a Mirror:
- With arms at your sides, then raise above your head, look carefully for changes in the size, shape, and contour of each breast. Look or puckering, dimpling, or changes in skin texture.
- Gently squeeze nipples and look for discharge.

Lying Down:
- Place a towel or pillow under your right shoulder and your right hand behind your head.
- Examine your right breast with your left hand.
- Fingers flat, press gently in small circles, starting at the outermost top edge of your breast and spiraling in toward the nipple.
- Examine every part of the breast.
- Repeat with left breast.

Sitting:
- With your arm resting on a firm surface, use the same circular motion to examine the underarm area. This is breast tissue too.
BRAS

Bra use after breast cancer surgery is based on what is comfortable for you and the type of surgery performed. Some women prefer to go braless. With any bra it is important that it does not rub or irritate the incision area and drains.

Features of a well fitting bra include:
1. No underwires
2. Wide adjustable padded shoulder straps to avoid collarbone pressure
3. Wide side panels to support the side of chest
4. No constriction or binding in any areas, especially around the trunk

Women with breast conserving surgeries may be more comfortable with a bra immediately following surgery to provide support and prevent movement of the remaining breast tissue. A well-fitting bra can minimize discomfort especially by sleeping in it. A sports bra is often softer and more comfortable. Be comfortable, bra or braless, whatever best meets your needs.

Women undergoing a mastectomy may find that a bra is uncomfortable on the incision and choose to wear nothing or a loose fitting man’s cotton tee shirt under their clothing. If a bra is desired, select a lightweight bra or a sportsbra used with a temporary soft fiber prosthesis.

If you were fitted with a special bra at the time of surgery, use it until you return to your doctor’s office. Do not let the bottom band of the bra roll up and put pressure on the breast.

PROSTHESIS

Prosthesis is an artificial body form molded as a breast that is worn inside the bra. If breast cancer surgery resulted in removal of the breast, then you may choose to wear breast prosthesis to restore body image and improve posture. If only part of the breast was removed as in a lumpectomy or quadrantectomy, then a partial prosthesis called an equalizer may be used. A wide variety of prosthesis exists including a temporary that is available through Reach to Recovery. A temporary prosthesis is a soft fabric fiber-filled form that can be placed in the bra or another version is a post-surgical undergarment with prosthesis. This can be worn until the surgeon gives a release to wear a permanent prosthesis which usually occurs after the mastectomy incision has healed in about four to six weeks.

Selection of a permanent prosthesis requires choosing a lightweight form that is convenient and comfortable as well as close in size and appearance to the remaining breast. A wide variety of prosthesis exists varying in materials, consistency, texture, and attachments. A prosthetic fitter will display all the selections available and help you make the right choice for your needs, size and lifestyle. Prosthesis can be purchased at local prosthesis shops, which specialize in fitting prosthesis and bras. They can also show you how to alter clothing such as swimwear, lingerie, and sportswear.
DES MOINES AREA PROSTHESIS SUPPLIERS

It is recommended to contact your insurance benefit office for approved prosthesis suppliers.

1. A-1 Home Healthcare Center
   2915 Ingersoll Ave
   Des Moines, IA 50312
   515-277-9500 -or- (800) 373-9500

2. American Cancer Society
   Reach to Recovery Program
   8364 Hickman Road
   Des Moines, IA 50325
   515-253-0542

   3005 86th Street
   Urbandale, IA 50322
   515-244-4040

4. Fittings Unlimited, Inc
   2793 100th St.
   Urbandale, IA 50322
   515-727-1406

5. Hair Care on Fifth
   1105 5th Street
   Nevada, IA 50201
   515-382-6633

6. Hammer Medical Supply
   1801 2nd Avenue
   Des Moines, IA 50314
   515-243-2886

7. Hammer Medical Supply
   8465 Hickman Road
   Urbandale, IA 50322
   515-225-0838

8. Home Care Medical Equipment
   405 S Clark, #275 (located St. Anthony’s Hospital - 2nd floor)
   Carroll, IA 51401
   712-792-4591

9. Iowa Home Health Care
   Women’s Health Boutique
   12695 University Avenue, Suite 120
   Clive, Iowa 50325
   515-225-6893

10. Mercy Cancer Center
    411 Laurel, Suite 1A
    Des Moines, IA 50314
    515-643-8206
11. **Personally Yours**  
601 SE Jackson  
Des Moines, IA  50315  
515-557-1938

12. **Stacey’s Bra and Lingerie Shop, Inc.**  
11161 Plum Drive  
Urbandale, IA 50322  
515-226-9336

13. **Von Maur**  
Valley West Mall  
West Des Moines, IA  50265  
515-223-1311 ext. 686

Also check with local department stores for alternative bra selections.
Look Good…Feel Better

Look Good…Feel Better is a program founded in 1989 to help women offset appearance-related changes from cancer treatment; essentially a “make-over”. The possibility of side effects including hair loss, and skin, facial and nail changes varies with different drugs and treatments. Ask your doctor about your particular course of therapy and any steps you can take to meet the challenges of these potential and typically temporary side effects.

Perhaps you’re concerned about maintaining the look of a full head of hair — for career needs, special events or simply your own peace of mind. Or maybe you’ve already lost some hair and want to get your favorite look back now. Our experts can help you prepare, cope and make stylish choices to look good…feel better.

Experiencing skin, facial and nail changes during cancer treatment? You can still be yourself. Our make-over expertise will show you the way to look good…feel better. Personal attention and hands-on tips and techniques from a trained cosmetologist can help you customize your look in a supportive atmosphere.

Not every woman approaches the very personal changes of cancer treatment in the same way. And not every woman adopts the same style solutions to look good…feel better. In fact, the options you learn about — from make-up to wigs to turbans to swimsuits to camisoles - will help you reflect your personal style.

For more information, call (515) 241-4243.