Inflammatory Breast Cancer (IBC)

THE UNIVERSITY OF TEXAS
MD Anderson
~~Cancer~~ Center
Making Cancer History®

Inflammatory Breast Cancer

Inflammatory breast cancer (IBC) appears as a breast skin discoloration, most often redness (erythema) with swelling (edema) of the skin of your breast. Skin may also be thick and dimpled. This is called “peau d’orange” which means skin of orange because the skin looks like an orange peel. IBC is rare. It can be hard to diagnose and can spread quickly.

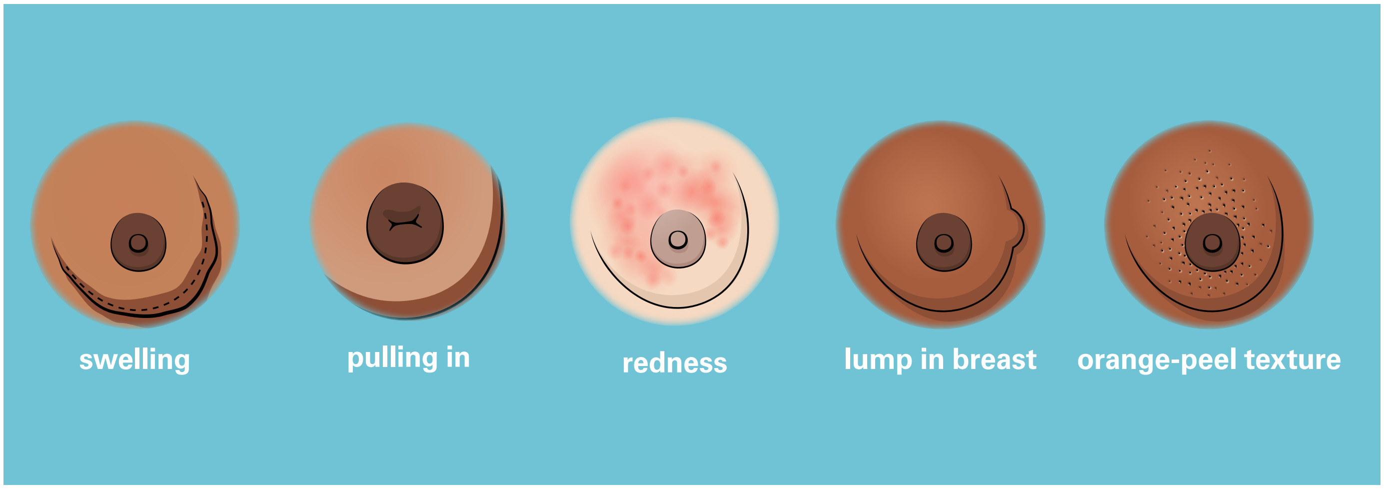
Signs and Symptoms

Signs and symptoms of IBC often appear within 3 to 6 months. They may include:

- Breast swelling
- Nipple changes including flattened or inverted nipple
- Redness or other changes to your breast skin color
- Breast warmth, with or without a lump
- Dimpled texture of your breast skin (peau d’orange)

Diagnosing IBC can be hard. A clear photo of your breast symptoms before you start treatment can be helpful. The photos can be used to calculate an “IBC score” to determine the chance that the symptoms are IBC. You can read more about the IBC score at [www.Komen.org/IBC-Calculator-Intro/.](www.Komen.org/IBC-Calculator-Intro/)

The images shown are examples of IBC breast changes: swollen breast, nipple inversion or pulling in, redness, engorged breast lump, and peau d’orange or orange-peel look.



IBC Diagnosis

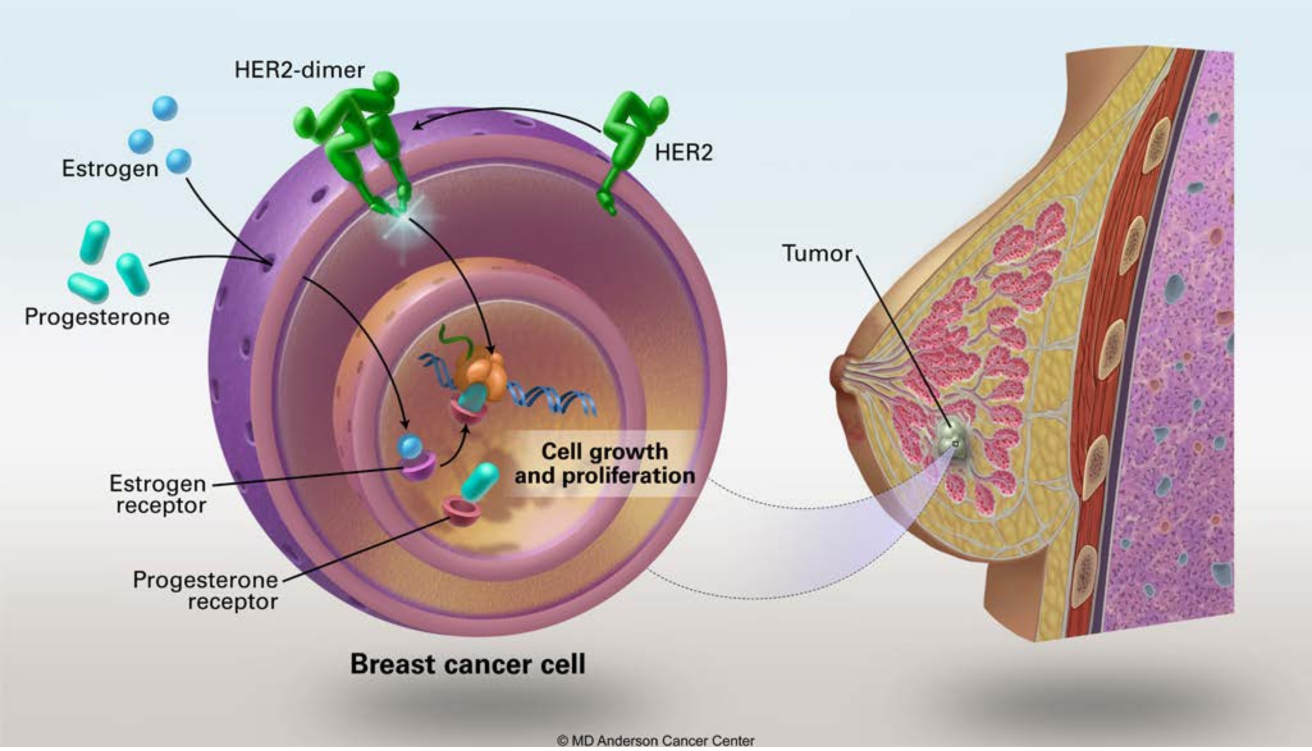
During the clinical exam to diagnose IBC, tests are performed on the tumor tissue from your biopsy. This information is used to determine the subtype and stage (spread) of the cancer and to prepare you to receive treatment.

IBC Subtype

There are different types of IBC known as molecular subtypes, which are defined by the presence or absence of particular proteins on the cell surface.

The subtype of IBC is important because the type of systemic (whole body) treatments recommended are different based on the subtype. There are 3 major subtypes of IBC based on proteins on tumor cells.

- **Hormone Receptor-positive:** The tumor cells have estrogen receptor (ER) or progesterone receptor (PR). Hormones cause the cancer to grow. Targeted treatment for these cancers blocks the hormone receptors and starves the tumor cells.
- **HER2-positive:** The tumor cells have human epidermal growth factor receptor 2 protein (HER2). These tumors respond to targeted medicines that attack this protein.
- **Triple negative (TN-IBC):** The tumor cells **do not** have ER, PR or HER2. Therapies that target these proteins will not work. Other treatments such as chemotherapy and immunotherapy are used to treat TN-IBC. Research is being done to develop new treatments for this group of cancers.



IBC cells with receptors on the cell surface that show subtype. The 3 receptors are ER, PR and HER2. The presence or absence of these proteins provides clues into the best treatment choices and overall prognosis.

Notes

IBC Staging

Scans such as a PET-CT or CT and bone scans are used to find out if IBC has spread in the body (staging). Staging for IBC starts at stage III. There is not a diagnosis at stages I and II. Stage III means the cancer is only in your breast and lymph nodes in the armpit on the same side as the breast cancer. If the cancer has spread to the other side of your body or to other organs such as your lung, liver or bone, the cancer is stage IV. Both stages are often treated the same. About 30% (3 out of 10) of IBC patients are diagnosed at stage IV.

Genetic Testing and Tumor Sequencing

When you are first diagnosed, you may be offered genetic testing. This is to check your normal cells in a blood sample. The goal of genetic testing is to see if your IBC may have resulted from inherited genes such as BRCA1 or BRCA2. These changes are important because they may also raise your risk for other cancers. They may also lead to new treatment choices for your IBC such as PARP inhibitors for BRCA1 or BRCA2 mutation carriers.

Your health care team will review the genetic testing results with you. If you carry a genetic mutation that needs attention, you may need screening procedures for other cancers or surgery to lower your risk. Your treatment for IBC will come first.

The more that is known about the details of your cancer, the better it can be treated. To improve treatment, you may be offered DNA sequencing of your tumor. This is to find out which changes are found in the tumor and its genes. These results may be used to identify available targeted therapies and clinical trials.

Treatment

You will see many members of your health care team during your treatment. They include:

- **Medical Oncologist:** Diagnoses and treats cancer using chemotherapy or chemo, immunotherapy, hormone, biological and other targeted therapies.
- **Surgical Oncologist:** Treats cancer with surgery to diagnose and remove tumors.
- **Radiation Oncologist:** Uses radiation to treat cancer and areas where cancer cells may remain.
- **Advanced Practice Provider:** A nurse practitioner or physician assistant who treats and cares for patients under the supervision of a doctor.
- **Pharmacist:** Instructs patients about medicines and treatment therapies.
- **Research Nurses and Study Coordinators:** Coordinates enrollment in clinical trials or laboratory studies about IBC.
- **Social Work Counselors:** Helps patients get care for IBC for non-medical needs such as travel and family issues.

Standard treatment for stage III and often stage IV IBC starts with systemic or targeted therapy. This may include immunotherapy given into a vein. In most cases, next steps include surgery and radiation which takes 4 to 6 weeks. Then, hormone therapy or more targeted therapy if these are right for your tumor type. It is very important to get chemo, surgery and radiation unless they cannot be done. Together, these 3 treatments are called tri-modality therapy.

Many patients are asked to participate in clinical trials. These include new treatments for newly diagnosed patients or those with recurrence. Your doctor will explain the benefits and risks of participating in a trial.

Systemic Treatment

The first treatment in IBC is often systemic therapy, which is treatment that targets the whole body. It may include chemotherapy or targeted therapy. This is called pre-operative or neoadjuvant therapy because it happens before surgery. The goal is to shrink the tumor and treat cells in the blood of other organs that cannot be seen with imaging but could be moving around in your body. Imaging tests are done halfway through systemic therapy and before surgery to check on how you are responding to treatment.

Patients with IBC found only in the breast will often receive a taxane- or anthracycline-based chemo. Taxane-based chemotherapies include:

- Paclitaxel (Taxol®)
- Docetaxel (Taxotere®)
- Carboplatin and paclitaxel

Anthracycline-based chemotherapies include:

- Doxorubicin (Adriamycin®) and cyclophosphamide (Cytoxan®)
- Fluorouracil, epirubicin (Ellence®) and cyclophosphamide
- Fluorouracil, doxorubicin (Adriamycin®) and cyclophosphamide

If the tumor cells have HER2 that expresses or cause change in DNA at a very high level, anti-HER2 targeted therapy is used along with chemotherapy.

Targeted Therapy

Targeted therapy uses medicines to find and attack specific cancer cells. This limits harm to normal cells. Some types of targeted therapy can kill cancer cells directly by affecting how the cells grow and survive. Trastuzumab (Herceptin®) and pertuzumab (Perjeta®) are targeted therapies often used first for IBC. They directly target HER2 proteins.

Other targeted therapies help the body's immune system or its natural defense attack and fight the cancer. This is called immunotherapy. Many cancers, such as IBC, slow down the body's immune response to not be destroyed. The body can help fight cancer by removing these blocked signals. Immunotherapy called pembrolizumab (Keytruda®) is given along with chemotherapy for TN-IBC. The goal is to shrink the tumor more than with chemotherapy alone.

Surgery

The recommended surgery is a mastectomy which removes the breast and all of the breast skin. Partial mastectomy or lumpectomy is not an option because this procedure may leave some cancer behind.

Surgery to remove the lymph nodes in your armpit is done because the cancer has often spread to nearby lymph nodes by the time of diagnosis. For IBC, the surgery to remove lymph nodes is an axillary lymph node dissection. It removes all level 1 and 2 lymph nodes from under the arm. You will not have a sentinel lymph node procedure. It is used for other types of breast cancer and does not work well for IBC. When the lymph nodes are removed, you are at a higher risk for your arm to swell, which is called lymphedema. Due to this risk, during your surgery your surgeon may work with a plastic surgeon to connect the cut lymph vessels to a vein. This will help to keep the flow of your arm fluid connected and may prevent arm swelling.

Radiation

The first step of radiation planning includes a CT scan to locate the area to receive radiation. The radiation team can then create the safest plan for you.

After surgery, radiation uses high-energy X-rays to kill any cancer cells that were left on the chest wall or in lymph nodes. These lymph nodes are under the breastbone and collarbone, and were not removed during surgery. Radiation that comes from a machine outside the body is called external beam radiation therapy. You cannot feel radiation. Radiation is always recommended after mastectomy for patients with IBC even if the surgery sample shows no sign of cancer cells after systemic therapy.

Radiation is specific to each patient. Your dose and treatment schedule can vary. Radiation treatment may last 4 to 6 weeks, with treatments every day or 2 times a day from Monday through Friday.

Reconstructive Surgery

You will have a detailed discussion with your care team regarding their recommendations for breast reconstruction. Reconstruction is often delayed 6 to 12 months after you complete radiation to allow for healing.

Some women choose to have reconstruction while others do not. There is no hurry to do so. Some women wait several years and combine reconstruction with surgeries to manage lymphedema.
If you are taking additional systemic therapies after radiation, you may need to wait longer to have your reconstruction completed safely.

Breast reconstruction can involve many surgeries. This process may take months and up to a year.

Often surgeries are performed on both breasts, even if only one breast had cancer, so that the breasts will look similar. Breast reconstruction for IBC patients is unique and may differ from those of breast cancer patients who do not have IBC.

You might choose a different option, such as using a breast prosthesis. This would help avoid more surgeries. A prosthesis fits inside a bra to create the look of a breast.

Hormone Therapy

If the tumor cells have estrogen (ER) or progesterone (PR) receptors, you may need hormone therapy. You will receive hormone therapy for 5 to 10 years after surgery to lower the risk of the cancer coming back. Pre-menopausal patients with ER-positive IBC also need to stop ovarian function or remove their ovaries to lower the amount of estrogen produced. You may also need to take other oral medicines such as targeted therapies to lower the risk of IBC coming back.

Frequently Asked Questions about IBC

Systemic Treatment

Q. Do I need a port before I start chemotherapy?
A. Most patients get a port at some point during IBC treatment. It is not necessary to have one before you start chemo. A port can improve your experience with intravenous (IV) therapies. A port can help limit problems from your veins becoming damaged over time due to treatments and blood draws. It is common to start chemo then get the port, if needed, after 1 or a few treatments.

Q. How does staging affect IBC treatment?
A. IBC is always diagnosed at stage III or IV. Patients who have stage III cancer receive treatment with the hope of curing the cancer. Patients with stage IV cancer receive treatment for the rest of their lives as there is no cure. Patients with stage IV cancer are closely monitored and treatment may be changed if it is not working or too harmful. Some stage IV patients reach no evidence of disease or "NED" status and can do very well for many years.

Q. Why do some patients get immunotherapy but not others?
A. Immunotherapy is used in patients with triple-negative breast cancer. This is based on large research studies that show better outcomes when added to chemotherapy. In the future, immunotherapy may be offered to more patients if research shows it is helpful.

Surgery

Q. Why is surgery not the first treatment for IBC?
A. Surgery is not an option until chemotherapy has had a chance to shrink the cancer. It takes 4 to 6 months of chemotherapy to shrink and kill the cancer before surgery is an option.

Q. Why is a non-skin-sparing mastectomy the recommended surgery for IBC?
A. IBC may or may not have a lump. Therefore, surgery that focuses on a lump, such as a lumpectomy, would not be beneficial. It is important to remove any live cancer that may have remained in your breast after chemotherapy. The best way to get rid of all the cancer is to remove the whole breast and overlying skin in a modified radical or total mastectomy.

Q. When can I have reconstruction?
A. Reconstruction is considered 6 to 12 months after you complete radiation. This is because immediate reconstruction may slow the success of other treatments. If you have any problems from surgery, or if an expander is placed, radiation may be weakened and will not properly treat your cancer. All patients are to wait until they heal after radiation before having reconstruction.

Q. Why are expanders not usually used for reconstruction in IBC?
A. Expanders are used at the time of mastectomy to stretch the skin enough to place an implant. Expanders are slowly filled with liquid to stretch the skin. Most IBC patients need radiation after mastectomy. Expanders are not used because they may block the area for radiation and affect how the skin stretches after radiation. Patients with expanders, after radiation, may have more problems which may need surgery to correct. Expanders can also lead to leaving skin with tumor cells that may cause recurrence.

Q. What are my risks for lymphedema? Is there anything I can do to reduce my risk?
A. Lymphedema, or swelling of the arm, results from surgery and radiation. Lymphedema can be a lifelong problem. Risk factors include being overweight, if all the lymph nodes were removed and if the axilla or underarm was treated with radiation. Many IBC patients have swelling or heaviness in their arms and are at a higher risk of a skin infection called cellulitis. Screening for lymphedema is available to help find it early.

Q. Should I have both breasts removed to prevent IBC from recurring?
A. Removing both breasts is not recommended for most patients when IBC is only in one breast. This is because surgery that is not needed has risks for problems. A problem with the breast that does not have IBC can slow down treatment for the breast with cancer. If recurrence is the concern, it is more likely for cancer to return in another organ than in the other breast.

Radiation

Q. Is proton therapy used for IBC?
A. Proton therapy may be a radiation option for IBC. Proton therapy may protect your heart and lungs from radiation exposure, which can be harmful. Talk with your radiation oncologist about the radiation plan that is best for you.

Q. Why do some patients get radiation 2 times a day?
A. Treatment is personalized for each patient. Patients who are at a higher risk for the cancer coming back may benefit from radiation 2 times a day. Patients who are younger than 45 or have a large amount of cancer left are offered radiation 2 times a day. This also depends on how well chemotherapy works for you.

Other Questions

Q. If I live out of state, can I receive some treatments near my home?
A. Yes, many patients can get systemic therapies which include chemo, immunotherapy or targeted therapies from their medical oncologist in their hometown. Your MD Anderson health care team will recommend the treatment schedule. However, decisions about how much medicine and how to manage side effects are made by the doctor who prescribes the medicines.

Surgery and radiation are more specialized for IBC. Many patients complete chemotherapy close to their homes. Then, they will have surgery and radiation at MD Anderson. It is hard to guide local teams on radiation treatment. Some patients may receive radiation 2 times a day, which is not often done outside of MD Anderson.

If you have housing or other travel concerns, talk with your health care team. Resources are available to help with your stay in Houston for the 4 to 6 weeks of radiation.

Resources

For more information on IBC visit MDAnderson.org/IBCProgram

CancerCare
CancerCare offers limited financial help for cancer-related costs and co-pays. Their oncology social workers can help find other resources. www.CancerCare.org/Financial_Assistance

Lindsay's Legacy Fund
This family-run non-profit has funds available in honor of a young lady who died from IBC. Her family wanted to make sure others with IBC had the resources to get the care they need. Lindsay's family has funds available to help women with financial barriers get prompt, expert medical attention needed to diagnose and treat IBC. www.LindsaysLegacyFund.com/

Susan G. Komen Foundation
Susan G. Komen Foundation runs a patient assistance program based on need. It is available to all breast cancer patients, including IBC. Apply online to see if you meet the eligibility criteria. www.Komen.org/Financial-Assistance-Program/

The IBC Network Foundation
The IBC Network Foundation funds IBC research. They also share information and provide education for the public and medical community. The IBC Network Foundation volunteers also strive to empower patients to seek IBC-specialty care and make educated treatment choices. TheIBCNetwork.org/

Patient Stories

To read about the experiences of other patients diagnosed with IBC, scan the QR codes:

Why I waited 10 years to have breast reconstruction

Inflammatory breast cancer survivor finds hope in clinical trial

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Inflammatory breast cancer survivor: I’m glad I went to MD Anderson

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Inflammatory breast cancer survivor finds hope at MD Anderson

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Stage IV breast cancer survivor thankful she can watch her child grow up

Notes

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Patient Education