GATHER YOUR TEAM
A support system can make the difference
In the fight for a cure for breast cancer, BRCA1 and BRCA2 get a lot of attention, but many people don’t understand how these genes’ mutations affect their risk of developing the disease. BRCA1 and BRCA2 (short for BReast CAncer 1 and 2) are human genes that produce tumor-suppressor proteins, according to the National Institutes of Health. These proteins help repair damaged DNA and play a role in cell growth and cell division. These are genes we all have in our bodies. It’s when these genes have mutations — or mistakes — that a person’s risk rises for developing breast and other forms of cancers, according to Memorial Sloan Kettering Cancer Center.

Only about 5 to 10 percent of all breast cancers diagnosed in the United States are due to inherited gene mutations known to increase risk, according to the American Cancer Society. The risk of developing breast cancer varies — it can double — depending on specific mutations within the genes, the study found. Having close family members with breast cancer also increased risk.

Other key findings:
• Among women who had not been diagnosed with breast cancer before the study, those with BRCA1 mutations faced a 72 percent chance of developing breast cancer by age 80, and the BRCA2 carriers had a 69 percent chance of developing breast cancer by age 80.
• The rate of new breast cancer cases increased rapidly among younger women, but leveled off around ages 30 to 40 for BRCA1 carriers and 40 to 50 for BRCA2 carriers.

A new study published in JAMA reveals how much having “breast cancer genes” increases the risk of cancer. Women with genetic mutations in the “breast cancer genes” have about a 70 percent chance of developing breast cancer in their lifetimes. The findings are based on an analysis of nearly 10,000 women with mutations in either the BRCA1 or BRCA2 gene.

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At the age of 12 to 15, many young women are experiencing the body and life changes that accompany adolescence. It can be difficult to imagine that breasts that are just beginning to develop may contain cancer. But such is the reality for some girls.

The majority of women who receive a breast cancer diagnosis are over the age of 40. Experts at Monroe Carell Jr. Hospital at Vanderbilt University note that only 5 percent of breast cancer cases are found in women under the age of 40. However, the hospital recently treated a 14-year-old girl who found a lump and learned she had a rare form of breast cancer called a phyllodes tumor. In 2009, a 13-year-old from Little Rock, Ark. found a quarter-sized lump in her right breast, while a 19-year-old student at the College of New Jersey was diagnosed with cancerous cells and underwent a bilateral mastectomy.

Though such cases are rare, it behooves teenage and adolescent girls to familiarize themselves with the disease and be mindful of their breast health.

Some organizations have increased breast cancer messages for young girls, and it is not uncommon to find young women participating in runs and fundraisers for breast cancer research. Some organizations even conduct breast cancer workshops to educate young women about breast health. Dorothy Paterson of Texas, a former Girl Scout leader who was diagnosed with breast cancer herself, began conducting workshops for Girl Scouts in 2007. The idea isn’t to scare girls into believing they have the disease, but rather to increase their awareness of changes in their bodies that may or may not be normal.

Some parents worry that educating children about breast cancer may cause them to worry unnecessarily, especially considering a young girl’s risk of developing breast cancer is so minimal. However, others see the importance in schooling girls early on about a disease that is so common. Advocates of teaching young girls about breast cancer often note that any effort to help save lives and promote health is worthwhile.

Just as with older women, adolescents and teens should realize that eating healthy foods, exercising, avoiding alcohol and tobacco, and maintaining annual physical exams with a doctor are key ways to reduce the risk for cancer.
Highly trained radiologists can detect small cancers so early through mammography that there now may be an overdiagnosis of small tumors, which can lead to unnecessary treatment, according to a Yale Cancer Center study.

“Radiologists are so skilled at finding tiny little tumors. It’s the price we pay. They're finding a lot of small cancers that will never become large and life-threatening,” said Dr. Donald Lannin, professor of surgery at Yale School of Medicine and lead author on the paper.

Many small cancers have an excellent prognosis because they are inherently slow-growing and treatable, such as with a lumpectomy, Lannin said.

Early detection doesn’t necessarily increase survival rates.
because these cancers will not grow large enough to become significant within a patient's lifetime, he said.

In contrast, large tumors that cause most breast cancer deaths often grow so quickly that they become dangerous before they can be detected by screening mammography.

Diagnosis not a death sentence

Before mammography it was thought that all cancers were life-threatening, and if cancer was detected earlier — when it was smaller — it would lead to higher survival rates, Lannin said.

Yet today mammograms only decrease breast cancer mortality rates by 19 percent, Lannin said.

“We would expect it to be higher, maybe 50 or 75 percent. We hoped for three decades to cut the risk by more,” he said.

As the science of mammography has accelerated diagnosis, radiologists are detecting “three times the amount of small cancers,” many of which are not life-threatening, Lannin said.

Previously, the medical community knew that there were differences in tumor growth rates but thought that the differences were small. What’s new from the Yale study is, researchers found that a large percentage of cancers grow quickly and another large percentage of cancers grow slowly, Lannin said.

“There’s a lot of bad breast cancers and also a lot of good breast cancers,” Lannin said. The diverse character of breast cancer explains both how mammography leads to overdiagnosis and also why it is not more effective.

What you should know

“Women shouldn’t have an over-optimistic expectation that a mammogram will keep you from dying from breast cancer,” Lannin said.

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He does not suggest women skip mammograms. Instead, they should “have some perspective” when faced with a diagnosis of a small breast cancer tumor, “which probably has a pretty good prognosis,” Lannin said.

The American Cancer Society suggests women 45 to 54 schedule a mammogram every year and after age 55 every two years, depending on health and family history.

Beyond that, treatment depends on the age of the patient and the biology of the cancer, Lannin said.

For a woman in her 50s diagnosed with a small slow-growing tumor, the cancer probably would have been diagnosed in her 70s without mammography, Lannin said. But a woman in her 70s diagnosed with a small slow-growing tumor may die of something else before the cancer grows large enough to be detected or be life-threatening, Lannin said.

The biology of the breast cancer also determines its treatment, Lannin said. Treatment depends on factors such as grade (how fast it grows), hormone receptors (how favorable the status of the estrogen and progesterone receptors are) and molecular testing. Those things determine how aggressively the cancer should be treated, Lannin said.
When facing a breast cancer diagnosis, there's strength in numbers. A new study finds that half of women relied on three or more people to help them process breast cancer treatment options.

"The big takeaway is that most women with early-stage breast cancer are involving multiple people — not just a spouse or partner — but other family, friends and colleagues to help them make informed decisions," said Dr. Lauren P. Wallner, assistant professor of general medicine and epidemiology at the University of Michigan and lead author of the paper, published in the journal Cancer.

Larger support networks were associated with more deliberation about treatment, which is critical as treatment options become more complex, Wallner said. More deliberation suggests patients are thinking through pros and cons, discussing it with others and weighing the decision carefully. The more people a woman has supporting her, the better her decisions are, Wallner said.

"When patients are diagnosed with cancer, there's this rush to get through the treatment process. But for patients with early-stage breast cancer, they have some time to decide on their treatment choice," Wallner said. "The idea that women are discussing their options more with their family and friends and potentially thinking through that decision more carefully is reassuring. Engaging these informal support networks could be a way to prevent women from rushing into something."

The study found that only 10 percent of women said they had no personal decision support network. Nearly three-quarters said their support network talked with them about their treatment options and frequently attended their appointments.

African-American and Latina women reported larger networks than did white women. Women who were married or partnered also reported more support.

Even among women without a partner or spouse, many had large support networks. Women reported children, friends, siblings, parents and other relatives were involved in their decision-making.

How you can help
Off to go with to an appointment and take notes. "It is incredibly helpful to have another set of eyes and ears," Wallner said.

Help with research
"If you're internet-savvy, help do research and track down information," Wallner said.

Just be there
"On a basic level, just being present lets the patient know she is not alone," Wallner said.

Doctors need to involve others
"Physicians should be aware that women want to include others in their treatment decisions," Wallner said.

A woman without a support network may need extra help or information during the decision process.

"It starts with something as simple as physicians asking patients who is helping them make their treatment decisions. That can then guide the conversation, such as the amount of resources the physician provides and to whom they communicate that information," she said.
Thousands upon thousands of women have battled breast cancer. Some have pulled through the disease, while others succumbed to the disease after a brave fight. Few people who have waged war with breast cancer are better known than Susan Komen, a name many instantly associate with the organization Susan G. Komen for the Cure, the most widely known, largest and well-funded breast cancer organization in the United States.

Susan G. Komen was born Susan Goodman in 1943 in Peoria, Ill. According to her sister, Nancy, Susan was the high school homecoming queen and a college beauty queen. After graduating from college, Goodman returned to her hometown and pursued modeling, eventually marrying her high school sweetheart, Stan.

Komen was diagnosed with breast cancer in 1977 after finding a lump that subsequent testing revealed was cancerous. Komen underwent a procedure called a subcutaneous mastectomy, in which the outside of the breast tissue was left intact, but the interior breast tissue was removed. The doctor who did the procedure assured Komen that she was cured. Despite urging her sister to get a second opinion, Komen was convinced she was safe. But within six months Komen found another lump under her arm, and, by this point, it was evident that the cancer had spread. Doctors at the Mayo Clinic soon determined the cancer had metastasized to her lung and under her arm.

Komen underwent several different treatments to slow the progression of the cancer, including radiation and intense chemotherapy. However, the cancer continued to spread and eventually her body developed a resistance to most of the medication. During treatment, Komen repeatedly spoke with her sister about her wish to make the entire breast cancer experience and treatments in the hospital more palatable for women, including improving the appearance of waiting rooms and treatment centers, and doing other things to help comfort those who would find themselves in similar situations in the future. Komen lost her battle with breast cancer in 1980 at age 36. By the time of her death, Komen had undergone nine operations and three courses of chemotherapy and radiation.

Nancy Goodman Brinker then made it her mission to do everything she could to help end breast cancer and increase awareness of this potentially deadly disease. In 1982, Brinker established the Susan G. Komen Breast Cancer Foundation in her sister’s memory. Since its inception, the organization, now called Susan G. Komen for the Cure, has provided funding for basic, clinical and translational breast cancer research projects. It also has become instrumental in breast health education and urging women to do self-screening while promoting annual mammograms. Through the years, the foundation has teamed up with many well-known businesses, brands and organizations as part of its fundraising efforts. To date, the organization has invested $750 million in breast cancer research, awarding many thousands of dollars in grants in countries around the world.

Through her struggle with breast cancer, Susan Goodman Komen unknowingly inspired an organization that has helped to save the lives of millions. Learn more at www5.komen.org.
Losing your hair is a common side effect of chemotherapy, yet it can be incredibly traumatic. There are beautiful ways to cope.

Hair should grow back after treatments are done, said Linda Whitehurst, a 28-year volunteer with Look Good Feel Better, a program that provides beauty workshops to improve self-esteem and quality of life for women undergoing chemotherapy, radiation and other cancer treatments.

Teaching women how to cover their heads with colorful scarves is one way to help them build their confidence and self-esteem.

“IT's all about the transformation and finding normalcy,” Whitehurst said.

Women going through a difficult time “don't want to stand out. They want to fit in,” said Deborah Flynn, manager of the Friends’ Place at Dana-Farber Cancer Institute in Boston.

Whether done in a workshop, by watching YouTube videos or simply by practicing in front of a mirror, there are endless possibilities to creatively manage the effects of hair loss. Scarves are a trendy alternative to wigs and hats, Flynn said.

“Wigs can be hot, and hats are not for everyone. Scarves are fashionable,” Flynn said.

They can be intimidating to someone who is not used to wearing them. Here are some of the experts' tips for how to tie, drape, twist and wrap a headscarf, as well as how to pick what's right for you.

Start square
Take a 30-by-30-inch square scarf. Fold it into triangle. Pull the front of the scarf over the forehead and knot the ends over the point in the triangle. Pull a bit of excess fabric above the knot to achieve a fuller look. You can also add a pair of socks to make it look like there's hair underneath.

Feeling rosy
Once you've tried a basic babushka, try the rosette turban. Use a large square or oblong scarf folded into a triangle. Place scarf on head with both ends to one ear and knot. Twist one end tightly and wind around knot. Tuck in the end and repeat with other end. If need be, hold ends in place with bobby pins.

Stay stable
Cotton scarves stay in place better than silky ones, Flynn said. ”For even more traction, wear a cotton beanie under the scarf to keep it in place,” she said.

Good choices
Scarves made of crinkled fabric are also good because they don't wrinkle, Whitehurst said. Other popular choices include tie-dyed or batik scarves with lots of color.

Not too far down
When placing a scarf on the forehead, avoid putting it too far down or else you'll end up with “the Cabbage Patch look,” Whitehurst said. Instead place it up near the hairline.

Scrunch the look
“It's hard to look at a beautiful scarf laid out flat and see what it will look like on. Take the scarf and roll it around in your hand. Scrunch it up in a coil to get a better idea of what it will look like when you're wearing it,” Whitehurst said.
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W
omen with early-stage cancer in one breast are increasingly choosing double mastectomies — even if they are at low risk of developing breast cancer in the other, healthy breast, a new study published in JAMA found.

Nearly half of women with early-stage breast cancer consider having a double mastectomy, and one in six received it.

“That one in six breast cancer patients chose bilateral mastectomy is really striking. We knew it was increasing, but I don’t think many of us realized just how frequent this is,” said study author Dr. Reshma Jagsi, professor and deputy chair of radiation oncology at the University of Michigan.

Myths and facts

The procedure is known as contralateral prophylactic mastectomy, in which the healthy breast is removed along with the cancerous breast. It’s an aggressive form of treatment that is recommended for women “who are at a very high risk of developing a new breast cancer” such as those with BRCA 1 or 2 mutations, family history or other risk factors, said Susan Brown, senior director of education and patient support for Susan G. Komen.

Especially concerning is the lack of knowledge about the procedure and its benefits, Brown said. Many women diagnosed with early-stage breast cancer decide on the most aggressive treatment with the belief that it will increase their rate of survival, Brown said.

“For a woman with average risk of developing a breast cancer in the second breast, a contralateral prophylactic mastectomy does not increase survival rates.”

Susan Brown, Susan G. Komen

Brown said.

Among patients who considered double mastectomy, only 38 percent knew it does not improve survival for all women with breast cancer, the study found.

Other misinformation muddies the decision-making process. For example, some patients think having a mastectomy on a healthy breast will stop them from having to undergo chemotherapy or other targeted therapies, but that is not true, Brown said.

“Contralateral prophylactic mastectomy will only reduce the risk of breast cancer developing in the healthy breast, but it doesn’t reduce the risk of breast cancer returning in the original breast or coming back later in another part of the body,” Brown said.

What you need to know

“Every surgery we perform can have potential complications. These need to be discussed and need to be taken into account carefully before decisions are made,” said Dr. Virginia Kaklamani, a medical oncologist and head of the breast cancer program at University of Texas Health San Antonio.

It’s important to understand the risks and benefits of treatment and how likely treatment is to positively affect survival rates, Brown said. There may also be post-operative complications, additional costs, and issues related to long-term suffering and quality of life, Brown said.

In the study, almost all patients said peace of mind motivated them to choose double mastectomy.

“They are afraid of another breast cancer, of more biopsies of going through this again,” Kaklamani said.

In these circumstances, a double mastectomy “can avoid years of anxiety and ongoing fears. For some women that’s a great benefit,” Brown said.
Breast cancer can affect both men and women and is one of the most common forms of cancer. Thanks to increased awareness and screenings, many cases of breast cancer are diagnosed early and treated successfully. BreastCancer.org says that invasive ductal carcinoma, or IDC, is the most common form of breast cancer, accounting for about 80 percent of all breast cancers. The American Cancer Society says that, although IDC can affect women of any age, it is most common among women age 55 or older. The good news is that this type of cancer is highly curable, provided it has not spread outside of the ducts to other breast tissue. Survival rates for any breast cancers diagnosed in the early stages are excellent.

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E

xercise helps keep a body healthy and lowers risk of some diseases. For women with cancer, physical activity can do many things, including control weight, improve mood, boost energy, increase sleep, and be fun and social — as long as exercise is done safely.

It is well-documented that physical activity benefits patients with cancer, both during and after treatment. Exercise helps patients combat physical and psychological impacts of cancer treatment, giving them a sense of well-being, control, stress reduction and empowerment.

So why aren’t more oncologists discussing exercise with their patients? A focus group study from Gundersen Health System in Wisconsin found that 95 percent of patients surveyed felt they benefited from exercise during treatment, but only three of the 20 patients recalled being instructed to exercise.

The investigators interviewed nine practitioners plus 20 patients 45 and older with two kinds of cancer: non-metastatic cancer after adjuvant therapy and metastatic disease undergoing palliative treatment, both across multiple tumor types. While the sample size is small, the study provides an understanding of how the group as a whole has the potential to influence the practice of physical activity recommendations.

The results indicated that exercise is perceived as important to patients with cancer, but physicians are reluctant to consistently include recommendations for physical activity in patient discussions, said Dr. Agnes Smaradottir, medical oncologist and lead investigator of the focus group study, which was published in the Journal of the National Comprehensive Cancer Network in May. A key finding was that physicians expressed concerns about asking patients to be more physically active while undergoing arduous cancer treatments.

“Regular exercise has been a part of the breast cancer treatment plan for years,” Smaradottir said. “Exercise regularly from the day you are diagnosed and beyond and have exercise be an important part of your life. Carve out time for exercise at least every other day. It is that important.”

For breast cancer patients, Smaradottir’s recommendations for exercise are:

- 150 minutes a week (30 minutes a day, five days a week) of moderate exercise or 75 minutes of vigorous activity.
- In addition, two to three sessions per week of strength training that includes major muscle groups and stretching.
- For women who have never exercised, start slower, working up to the goal of 150 minutes a week.
- For women already exercising, continue the exercise plan with adjustments during chemotherapy and radiation.

Before starting an exercise regime, talk to your doctor about weight loss, weight management and what types of exercise are safe for you to do. Walking is probably the simplest, easiest and the most inexpensive way to remain fit. Studies presented at the American Society of Clinical Oncology conference reported that just 25 minutes of brisk walking every day not only cuts the risk of cancer but also helps people battling the disease.

For moderate exercise, try walking briskly at a pace where you are able to talk but not sing, Smaradottir said.
Mammograms help to detect breast cancer early, improving women’s prognosis as a result. Susan G. Komen states that mammography is the most effective breast cancer screening tool in use today.

When women should begin getting mammograms remains open to debate. The American Cancer Society now recommends that women between the ages of 45 and 54 receive annual mammograms.

Despite the benefits of mammograms, many women avoid them out of fear of the pain and discomfort associated with the procedure. But researchers are examining how much pressure mammogram machines need to apply to get accurate breast images.

Until widespread customized mammograms are offered, women can take various steps to reduce the amount of discomfort they feel while undergoing these important screening procedures.

Apply a topical numbing gel. BreastCancer.org says a study found that applying a numbing gel an hour before having a mammogram resulted in less discomfort when compared to placebo and other pain-reduction techniques. Be sure to discuss application of the gel with your physician prior to your procedure.

Schedule your procedure for the right time.
Do not schedule a mammogram right before or during a menstrual cycle, when breasts already are very tender due to hormonal changes. Waiting until seven to 14 days after a period is a better bet.

Take pain relief pills.
A physician may suggest taking ibuprofen or acetaminophen prior to the appointment to reduce discomfort before and after the procedure.

Speak with the technician.
Women can express their concerns about pain to the mammogram technician, who might suggest various ways to minimize discomfort.

Learn about padding.
Find an imaging center that uses padding on mammogram plates. MammoPad is a soft, white, single-use foam pad that is invisible to X-rays.

Avoid caffeine.
Some women find that caffeine contributes to breast tenderness. Avoid caffeine the week before the procedure.

Mammograms are an important health care tool. Reducing discomfort may encourage women to follow guidelines regarding mammograms more closely.

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Feeling a lump in the breast is a classic sign of breast cancer, but there are other less-well-known signals that can tip off potential trouble.

“The hope is that women know their own bodies and would find a mass before it becomes palpable, but the truth is that radiologists can find tumors so small — 3, 4 or 5 millimeters — that it’s rare to be able to feel a small tumor before it can be discovered by mammogram,” said Dr. Therese Bevers, medical director of the Cancer Prevention Center at MD Anderson in Houston and an expert in breast cancer screenings.

Today, breast self-exams are not widely recommended, but that doesn’t mean you should stop investigating your breasts, Bevers said. The keywords now are “breast awareness.”

“‘You know how your breasts look and feel. If something feels different, have it checked out,’” Bevers said.

“Women themselves discover ‘a substantial amount of breast cancer because nobody knows a woman’s body as well as she does herself,’” said Dr. Rachel Brem, director of breast imaging and intervention at The GW Medical Faculty Associates in Washington, D.C.

“You know how your breasts look and feel. If something feels different, have it checked out.”

Dr. Therese Bevers

Some of the signs of potential breast cancer:

- **Red, inflamed breast**
  A swollen and sometimes warm, red breast should be evaluated promptly, Bevers said. Inflammatory breast cancer is a rare but aggressive disease. Swelling and redness affecting one-third or more of the breast is cause for concern. Smaller changes, like the size of a half-dollar, are probably not breast cancer, “but get it diagnosed,” Bevers said.

- **Peeling, scaling**
  Flaky, peeling or scaling skin on the breast could be a sign of Paget’s disease, a type of breast cancer, or it could be minor skin irritation, Bevers said. Watch for whether the skin changes only occur in one breast, often starting in the nipple area, and spread from there.

- **Dimpling of the skin**
  “‘A dimpling on the skin of the breast like a pimple that doesn’t heal’” can also be a sign of breast cancer, Brem said. The nipple may also become retracted because there’s a tumor pulling it inward, Bevers said. The dimpling might be subtle and noticeable only at certain times, for example, when you stand in front of a mirror and raise your arms to brush your hair, Bevers said.

- **Nipple discharge**
  Most nipple discharge is not breast cancer, but it is of more concern if it is spontaneous, from one breast only, or clear rather than milky or greenish, Brem said. Nipple discharge may not have a high suspicion rate, but have it checked out.

- **Mass in the armpit**
  An ancillary mass in the region, such as a lump in the armpit, could be breast cancer in the lymph nodes, Bevers said. “Not all lumps in the armpit are breast cancer. It could be an ingrown hair, but it needs to be checked out,” she said.

- **A thickening**
  If your breast feels firmer than before, that change should be evaluated by a doctor. “If it’s a change to you, it doesn’t matter what you can see or feel,” Bevers said. Use your awareness of your breasts. If something doesn’t feel normal, get it checked out.
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