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REACH
TO RECOVERY
INTERNATIONAL

Reach to Recovery International (RRI)

RRI is committed to improving the quality of life of individuals affected by breast cancer and their families.

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Reach to Recovery International, Inc. is a global non-profit
organisation based in Baltimore, Maryland, USA.

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Our mission

Reach to Recovery International's mission is to:

- Unite organisations throughout the world which support individuals affected by breast cancer, including their families, in order to share ideas and best practices;
- Disseminate valuable information to support individuals affected by breast cancer throughout the world via bi-annual conferences, our website, our e-newsletter, and other forms of worldwide communications; and
- Assist our Member Organisations in achieving their goals of:
 - Improving the quality of life of individuals affected by breast cancer,
 - Providing psychosocial support to individuals affected by breast cancer, either through group meetings or activities or one-on-one peer support provided by carefully trained survivor volunteers,
 - Advocating on behalf of individuals affected by breast cancer,
 - Providing patient navigation to individuals affected by breast cancer.

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What would you like to read about in the next edition of *bloom*?

Email your theme suggestions to info@reachtorecoveryinternational.org. A theme will be chosen by August 2022. Regardless of whether your suggested theme is chosen this time, it will remain under consideration for future editions.



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Celebrate the work being done by your organisation's volunteers!

Do your organisation's volunteers do outstanding work to support those touched by breast cancer in your community? Bloom wants to hear all about it! Send us articles about the projects your volunteers are working on, and be sure to include high resolution photos. Articles should be 200 - 400 words long and should be sent in Word format to info@reachtorecoveryinternational.org. It's a great way to thank your volunteers for a job well done, and to raise awareness about your organisation!

Upcoming events:

World Cancer Congress

20 – 22 October 2022 / Geneva, Switzerland

www.worldcancercongress.org

World Cancer Day 2022

4 February 2022

www.worldcancerday.org



Message from Cathy Hirsch - President of RRI



Cathy Hirsch

Conference update:

It is with regret that I announce the cancellation of the 20th Reach to Recovery International Breast Cancer Support Conference. The Conference was scheduled to be held in Guadalajara, Mexico from 22 - 25 September 2022. It has already been postponed and rescheduled several times because of the COVID-19 pandemic. RRI's Board of Directors and advisors have determined that, unfortunately, international travel is still not practicable in light of the latest surge in COVID cases, the risk of infection, and the effect the pandemic continues to have on the availability and price of flights as well as the world economy in general. We therefore made the very difficult decision to cancel the Conference. We apologize for the inconvenience to anyone who was making plans to attend.

We understand that the local organizing committee in Guadalajara intends to continue with plans for a breast cancer support conference on the same dates and in the same location. Please be aware that this will not be a Reach to Recovery International Conference.

RRI is now in the process of planning a series of virtual sessions that will be of interest to breast cancer patients, survivors, caregivers, and volunteers. We had planned to present the 2022 Terese Lasser Award and Health Professional Medal and to introduce RRI's next President and new Board members at the Conference, but we are now reviewing other options for the awards and announcements.

In this edition of Bloom:

Ductal Carcinoma in Situ, or DCIS, is a type of breast cancer that many patients find confusing. We hear it referred to as Stage 0, pre-invasive, intraductal, or non-invasive breast cancer. But it *is* possible for DCIS to develop into invasive cancer, so those who receive a diagnosis of DCIS

experience the same shock and fear as those with other forms of breast cancer. On the one hand they're told they are lucky that it has been caught early enough to be cured; on the other they still have to pursue treatment which may involve disfiguring surgery and unpleasant side effects, and they may suffer from the same body image and sexuality issues that other breast cancer patients face.

In this edition of Bloom, we take a close look at DCIS and examine what it is, how it is treated, the mixed feelings patients may have about the diagnosis, and the supportive care needs of patients. We hear the perspectives of medical professionals based in Australia, Egypt, Malaysia, and the US, and we have personal stories from DCIS survivors from around the world.

Although we will not have the pleasure of visiting Guadalajara and enjoying its hospitality and delicious cuisine, the local organizing committee there has graciously provided us with some healthy Mexican recipes so we can sample a little bit of their culture at home.

“ RRI IS NOW IN THE PROCESS OF PLANNING A SERIES OF VIRTUAL SESSIONS THAT WILL BE OF INTEREST TO BREAST CANCER PATIENTS, SURVIVORS, CAREGIVERS, AND VOLUNTEERS. ”

Ductal Carcinoma in Situ

Cheng Har Yip, Consultant Breast Surgeon

Professor Emeritus, University of Malaya, Kuala Lumpur, Malaysia



Cheng Har Yip

Ductal carcinoma in situ is also known as non-invasive breast cancer or Stage 0 breast cancer. It comprises over 20% of all breast cancers in high income countries where screening mammography is available. In low and middle income countries where mammography screening is not available, it comprises less than 5% of all breast cancers. This may be because DCIS is most often diagnosed during a screening mammogram, and usually, there is no palpable lump.

Breast cancer usually starts from the lining of the breast milk ducts and, if the cancer cells remain in the ducts, it is called ductal carcinoma in situ. Once the cancer cells break out from the lining of the ducts, it becomes an invasive ductal carcinoma.

The risk of the cancer cells breaking out from the lining of the milk ducts and becoming a breast cancer depends on several factors, the most important of which is the grade of ductal carcinoma in situ. Similar to invasive ductal carcinoma, DCIS is also graded 1, 2 or 3. Grade 1 DCIS may never become breast cancer, whereas Grade 3 DCIS has a high chance of becoming invasive breast cancer. Estrogen and progesterone receptors (ER and PR) are also tested in DCIS. While human epidermal growth factor 2 (HER2) is more likely to be positive in DCIS compared to invasive breast cancer, it is generally not tested in DCIS since it does not impact treatment recommendations. Current research aims to identify biomarkers that could predict a highly aggressive subtype of DCIS that will progress to invasive breast cancer, so that these can be treated more aggressively.

Overall, DCIS carries a 30 to 60% risk of becoming an invasive breast cancer. Although some DCIS may never become invasive breast cancer, screening mammography is still recommended. An individual diagnosed with DCIS may undergo surgery with or without radiotherapy and should be aware of possible side effects of these treatments.

DCIS may initially present as a lump in the breast or as a screening abnormality, and is diagnosed by a biopsy of the breast abnormality. A core needle biopsy is preferred over a fine needle biopsy.

DCIS is treated the same way as an invasive breast cancer. Surgery is the mainstay of treatment. The options for surgery are either lumpectomy or mastectomy, based on the size of the lesion and whether there is multifocality. About 20% of the time, the diagnosis may be upgraded to invasive breast cancer after surgery because the core needle biopsy only samples parts of the cancer and may not show invasion.

Lymph node staging is generally not required, as DCIS usually does not spread to the lymph nodes. Radiation therapy may be required after lumpectomy. The OncotypeDX

DCIS score can be used to determine whether radiotherapy can be avoided in women with low risk DCIS who had breast conserving surgery (i.e. lumpectomy).

Chemotherapy is not required for DCIS. For women with DCIS that is ER positive, tamoxifen reduces the risk of contralateral breast cancers, and reduces risk of ipsilateral local recurrence (if lumpectomy is performed).

Certain low-risk DCIS that may never progress to invasive breast cancer may be able to be observed closely. The LORD (Low risk DCIS) study is a non-randomized, international, multicentre, phase III non-inferiority trial to determine whether low-risk DCIS (Grade 1 and 2) detected on screening mammography can be managed with active surveillance rather than standard treatment.

DCIS is a non-invasive breast cancer with an excellent prognosis, and almost 100% cure rate if properly treated. It often presents as microcalcifications detected on mammographic screening and is the earliest form of breast cancer. Randomized controlled trials have shown that screening mammograms lead to a reduction in breast cancer mortality.

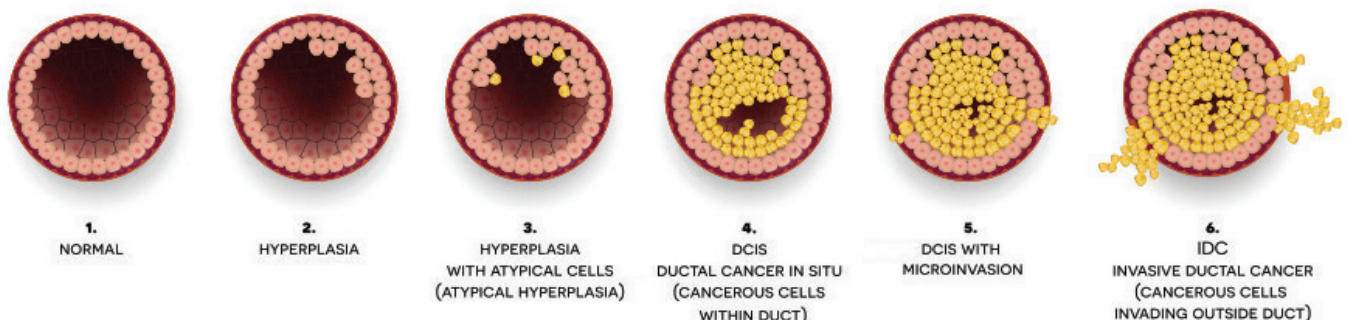


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Types of Breast Cancer

Ductal Carcinoma In Situ (DCIS)

Ductal carcinoma in situ (DCIS) is non-invasive breast cancer that starts in the milk ducts.

Symptoms of DCIS

DCIS generally has no symptoms. In some cases, DCIS may cause a lump or nipple discharge. But in most cases, DCIS is found by mammogram where it looks like small clusters of white spots.

Diagnosis of DCIS

Diagnosing DCIS involves a combination of procedures and almost always includes:

- [breast physical exam](#)
- [mammogram](#)
- [biopsy](#)

Other tests that may be used are:

- [ultrasound](#)
- [breast MRI](#)

Staging DCIS

DCIS is [stage 0](#) breast cancer, the earliest stage possible.

DCIS grade

Because all DCIS is stage 0, your doctor will also use the grade of the DCIS to decide on the best treatment options for you. The grade describes how much the cells look like healthy breast cells.

There are three grades of DCIS:

- **Low-grade or grade I** DCIS cells look only a little bit different from healthy breast cells and grow slowly. Low-grade DCIS is less likely to come back (recur) than moderate- or high-grade DCIS.
- **Moderate-grade or grade II** (also called intermediate-grade) DCIS cells look more different from healthy breast cells than low-grade DCIS and grow faster. Moderate-grade DCIS is more likely to come back than low-grade

DCIS, but less likely to come back than high-grade DCIS.

- **High-grade or grade III** DCIS cells look much different from healthy breast cells and tend to grow more quickly. High-grade DCIS has a higher risk of coming back than low- or moderate-grade DCIS. High-grade DCIS may be described as comedo or comedo necrosis, which means there are areas of dead cancer cells inside the DCIS.

Your doctor will likely do other tests to collect more information on the characteristics of the DCIS. These tests, as well as the results of your biopsy, make up the parts of your [pathology report](#).

Information that may be part of your DCIS pathology report includes:

- size of the DCIS
- hormone receptor status
- tumor margins
- rate of cell growth (Ki-67 levels)

Treatment of DCIS

Standard treatments for DCIS are:

- [lumpectomy](#) followed by [radiation therapy](#)
- [lumpectomy](#) alone, if the DCIS is very small and low-grade
- [mastectomy](#)
- [hormonal therapy](#), if the DCIS is hormone-receptor-positive

The [Oncotype DX Breast DCIS Score Test](#) can help you and your doctor decide if radiation would offer benefits after lumpectomy to remove the DCIS.



For more information about survivorship care after DCIS treatment, visit <https://www.breastcancer.org/types/ductal-carcinoma-in-situ>.

Understanding Ductal Carcinoma in Situ

Prof. Dr. Karima Elshamy, DNS, *Faculty of Nursing, Mansoura University, Egypt; Founder and Executive Director of Egyptian Society for Promoting Women's Health*



Dr. Karima Elshamy

Overview

The introduction of mammographic screening programs for breast cancer has been followed by an increase in the diagnosis of ductal carcinoma in situ (DCIS). The benefit of finding DCIS is that steps can be taken to prevent it from developing into invasive breast cancer. The aim of this article is to improve understanding of the diagnosis of DCIS and to inform decisions about the treatment of DCIS:

- What ductal carcinoma in situ (DCIS) is
- How DCIS differs from invasive breast cancer
- Why it's important to treat DCIS
- How successful different treatments are for DCIS

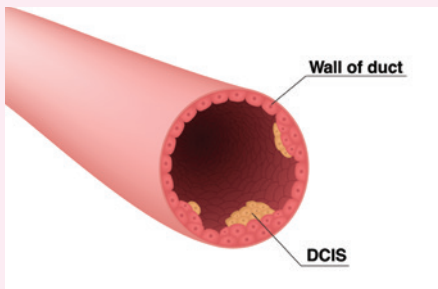


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Understanding Ductal Carcinoma in Situ (DCIS)

To understand what DCIS is, it helps to know what your breast looks like on the inside. The breast contains lobules (milk sacs) that produce milk, and ducts that take the milk to the nipple. These are surrounded by fatty tissue. Sometimes the cells on the inside of the milk ducts become abnormal in shape and size, and begin to multiply in an uncontrolled way. When cancer cells have developed within the ducts of the breast but remain within the ducts (in situ) it is called DCIS. The cancer cells have not yet developed the ability to spread outside these ducts into the surrounding breast tissue or to other parts of the body. As a result of being confined to the ducts, DCIS has a very good prognosis.

Ductal Carcinoma in Situ (DCIS) is an early form of breast cancer and accounts for about 20% of all breast cancers. In DCIS, the cells that line the milk ducts of the breast have become cancer, but they have not

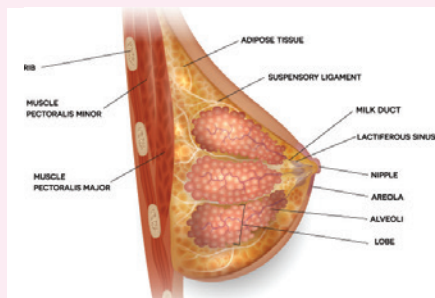


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spread into surrounding breast tissue. DCIS is diagnosed more often now than in the past. It is often picked up in women when they have screening mammograms. DCIS is considered non-invasive or pre-invasive breast cancer. DCIS can't spread outside the breast, but it still needs to be treated because it can sometimes go on to become invasive breast cancer (which can spread).

Is Ductal Carcinoma In Situ A Type Of Cancer?

This is a controversial topic, partly due to the language. It has the word "carcinoma" in the name, and it is classified as stage 0 cancer. So DCIS isn't life-threatening, but it has the potential to become invasive cancer. You may hear DCIS described in different ways such as a pre-invasive, intraductal, non-invasive cancer.

What's The Difference between DCIS and Invasive Breast Cancer?

The abnormal cells seen in DCIS are cancer

cells. However, DCIS is not breast cancer as we commonly understand it. In breast cancer, the cancer cells have spread out of the milk ducts into the surrounding breast tissue. That is why it's sometimes called 'invasive' breast cancer.

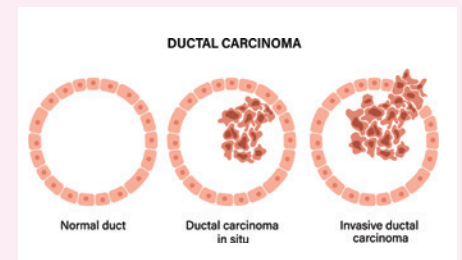


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What Are The Symptoms Of DCIS?

DCIS usually has no symptoms. Most cases of DCIS are found during routine breast screening or if a mammogram (breast x-ray) is done for some other reason. Occasionally DCIS is found when someone has a breast change such as a lump or discharge (liquid) from the nipple. However, if someone with DCIS has a breast change it's more likely they will also have an invasive breast cancer.

Some people with DCIS also have a type of rash involving the nipple known as Paget's disease of the nipple, although this is rare.

Causes of Ductal Carcinoma In Situ

It's not clear what causes DCIS. DCIS forms when genetic mutations occur in the DNA of breast duct cells. The genetic mutations

cause the cells to appear abnormal, but the cells don't yet have the ability to break out of the breast duct.

Researchers don't know exactly what triggers the abnormal cell growth that leads to DCIS. Factors that may play a part include: your lifestyle, your environment, and genes passed to you from your parents.

Risk factors of Ductal Carcinoma In Situ

Factors that may increase your risk of DCIS include:

- Increasing age
- Personal history of benign breast disease, such as atypical hyperplasia
- Family history of breast cancer
- Never having been pregnant
- Having your first baby after age 30
- Having your first period before age 12
- Beginning menopause after age 55
- Genetic mutations that increase the risk of breast cancer, such as those in the breast cancer genes BRCA1 and BRCA2

Diagnosis of Ductal Carcinoma In Situ

DCIS is diagnosed using a range of tests, these may include:

- A breast examination
- A mammogram (breast x-ray)
- An ultrasound scan (uses sound waves to produce an image)
- A core biopsy (using a hollow needle to take a sample of tissue, under local anaesthetic, to be looked at under a microscope, several tissue samples may be taken at the same time)
- A vacuum assisted biopsy (a hollow probe connected to a vacuum is used to take a sample of tissue, under local anaesthetic, to be looked at under a microscope)

Breast imaging

DCIS is most often discovered during a mammogram used to screen for breast cancer. If your mammogram shows suspicious areas such as bright white specks (microcalcifications), which are in a cluster and have irregular shapes or sizes, your radiologist likely will recommend additional breast imaging.

You may have a diagnostic mammogram, which takes views at higher magnification from more angles. This examination evaluates both breasts and takes a closer look at the microcalcifications to determine whether they are a cause for concern. If the area of concern needs further evaluation, the next step may be an ultrasound and a breast biopsy.

Removing breast tissue samples for testing

During a core needle biopsy, a radiologist or surgeon uses a hollow needle to remove tissue samples from the suspicious area, sometimes guided by ultrasound (ultrasound-guided breast biopsy) or by X-ray (stereotactic breast biopsy). The tissue samples are sent to a lab for analysis. In a lab, a doctor who specializes in analyzing blood and body tissue (pathologist) will examine the samples to determine whether abnormal cells are present and if so, how aggressive those abnormal cells appear to be.

How is DCIS Graded?

DCIS is graded based on what the cells look like under the microscope. They will be given a grade according to how different they are to normal breast cells and how quickly they are growing. DCIS is graded as:

- **Low grade:** the cancer cells look mostly like normal breast cells and are usually slow growing
- **Intermediate grade:** the cancer cells look less like normal breast cells and are growing faster
- **High grade:** the cancer cells look different from normal breast cells and may be fast-growing

Natural History of DCIS

Ductal carcinoma in situ is considered a precursor of invasive breast cancer. There is a risk of untreated DCIS progressing to invasive carcinoma in the ipsilateral breast 10–20 years after initial diagnosis. The cumulative risk of contralateral breast cancer is low (less than 1% per annum).

In some cases, DCIS will never develop further or grows so slowly that it would never cause harm during that person's lifetime. Although the size and grade of the DCIS can help predict if it will become invasive, there is currently no way of knowing if this will happen. High-grade DCIS is more likely to become an invasive breast cancer than low-grade DCIS and to do so more quickly.

Can DCIS Be Left Untreated?

Because there's no way of knowing when or if DCIS will become invasive, treatment is usually recommended. It is possible that this may lead to unnecessary or overtreatment for some people. The aim of treatment is to remove all the DCIS from within the breast to reduce the chance of it becoming an invasive cancer. Research is ongoing to identify which cases of DCIS will go on to become invasive and which might be safe to leave untreated. If you are diagnosed with low-grade DCIS, you may be invited to join a clinical trial.

Why Is DCIS Treated?

The aim of treating DCIS is to prevent invasive breast cancer from developing. If DCIS is not treated it may develop into invasive breast cancer, which can spread outside the ducts into the breast tissue and then possibly to other parts of the body. We don't know for certain how many women with DCIS would develop invasive breast cancer if they were not treated. Also, it is not possible to predict which women with DCIS will develop invasive breast cancer if they were not treated or how long after the diagnosis of DCIS an invasive breast cancer would develop. Some women with DCIS may never develop any problems if they are not treated. However, some women with DCIS may develop invasive breast cancer.

Because DCIS may develop into invasive breast cancer and invasive breast cancer can spread and cause death, women with DCIS are generally recommended to have treatment. Treatment for DCIS aims to help prevent invasive breast cancer from developing and DCIS from coming back in the breast. DCIS can be treated successfully and most women treated for DCIS will not later develop invasive breast cancer.

A focus of current research is to identify whether treatment for DCIS can vary dependent on the grade of the disease. There are currently international clinical trials, which are investigating the "watch and wait" approach compared to immediate treatment for the management of low-grade DCIS. The results from these trials will help to determine the best treatment options for women with low-grade DCIS. At this time, however, there are no national or international guidelines which recommend a "watch and wait" management option for low-grade DCIS.

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Treatment of Ductal Carcinoma in Situ

Prof. Dr. Karima Elshamy, DNS, *Faculty of Nursing, Mansoura University, Egypt; Founder and Executive Director of Egyptian Society for Promoting Women's Health*

Overview

Treatment of DCIS has a high likelihood of successfully removing the tumor and preventing recurrence.

In most people, treatment options for DCIS include:

- Breast-conserving surgery (lumpectomy) and radiation therapy
- Breast-removing surgery (mastectomy)

In some cases, treatment options may include:

- Lumpectomy only
- Lumpectomy and endocrine (hormone) therapy
- Participation in a clinical trial comparing close monitoring with surgery

Surgery

If you're diagnosed with DCIS, one of the first decisions you'll have to make is whether to treat the condition with lumpectomy or mastectomy.

Lumpectomy: Lumpectomy is surgery to remove the area of DCIS and a margin of healthy tissue that surrounds it. This is also known as a surgical biopsy or wide local incision.

The procedure allows you to keep as much of your breast as possible, and depending on the amount of tissue removed, usually eliminates the need for breast reconstruction.

Research suggests that women treated with lumpectomy have a slightly higher risk of recurrence than women who undergo mastectomy; however, survival rates between the two groups are very similar.

If you have other serious health conditions, you might consider other options, such as lumpectomy plus hormone therapy, lumpectomy alone or no treatment.

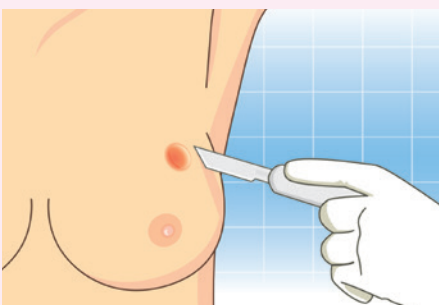


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Mastectomy: Mastectomy is an operation to remove all of the breast tissue. Breast reconstruction to restore the appearance of your breast can be done at the same time or in a later procedure, if you desire.

Most women with DCIS are candidates for lumpectomy. However, mastectomy may be recommended if:

- **You have a large area of DCIS.** If the area is large relative to the size of your breast, a lumpectomy may not produce acceptable cosmetic results.
- **There's more than one area of DCIS (multifocal or multicentric disease).** It's difficult to remove multiple areas of DCIS with a lumpectomy, especially if DCIS is found in different sections (or quadrants) of the breast.
- **Tissue samples taken for biopsy show abnormal cells at or near the edge (margin) of the tissue specimen.** There may be more DCIS than originally thought, meaning that a lumpectomy might not be adequate to remove all areas of DCIS. Additional tissue may need to be removed, which could require mastectomy to remove all of the breast tissue if the area of DCIS involvement is large relative to the size of the breast.
- **You're not a candidate for radiation therapy.** Radiation is usually given after a lumpectomy, but you may not be a candidate for radiation if: you're diagnosed in the first trimester of pregnancy; you've

received prior radiation to your chest or breast, or you have a condition that makes you more sensitive to the side effects of radiation therapy, such as systemic lupus erythematosus.

- **You prefer to have a mastectomy rather than a lumpectomy.** For instance, you might not want a lumpectomy if you don't want radiation.

Because DCIS is noninvasive, surgery typically doesn't involve the removal of lymph nodes from under your arm. The chance of finding cancer in the lymph nodes is extremely small. If tissue obtained during surgery leads your doctor to think that abnormal cells may have spread outside the breast duct or if you are having a mastectomy, then a sentinel node biopsy or removal of some lymph nodes may be done as part of the surgery.

Radiation therapy

Radiation therapy uses high-energy beams, such as X-rays or protons, to kill abnormal cells. Radiation therapy after lumpectomy reduces the chance that DCIS will come back (recur) or that it will progress to invasive cancer.

Radiation most often comes from a machine that moves around your body, precisely aiming the beams of radiation at points on your body (external beam radiation). Less commonly, radiation comes from a device temporarily placed inside your breast tissue (brachytherapy).

Radiation is typically used after lumpectomy. But it might not be necessary if you have only a small area of DCIS that is considered low grade and was completely removed during surgery.



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Endocrine (hormone) therapy

Endocrine (hormone) therapy is a treatment to block hormones from reaching cancer cells and is only effective against cancers that grow in response to hormones (hormone receptor positive breast cancer). Endocrine therapy isn't a treatment for DCIS in and of itself, but it can be considered an additional (adjuvant) therapy given after surgery or radiation in an attempt to decrease your chance of developing a recurrence of DCIS or invasive breast cancer in either breast in the future.

The drug tamoxifen blocks the action of estrogen — a hormone that fuels some breast cancer cells and promotes tumor growth — to reduce your risk of developing invasive breast cancer. It can be used for up to five years both in women who haven't yet undergone menopause (premenopausal) and in those who have (postmenopausal).

Postmenopausal women may also consider endocrine therapy with drugs called aromatase inhibitors. These medications, which are taken for up to five years, work by reducing the amount of estrogen produced in your body. If you choose to have a mastectomy, there's less reason to use endocrine therapy. With a mastectomy, the risk of invasive breast cancer or recurrent DCIS in the small amount of remaining breast tissue is very small. Any potential benefit from endocrine therapy would apply only to the opposite breast. Discuss the pros and cons of endocrine therapy with your doctor.

Alternative medicine

No alternative medicine treatments have been found to cure DCIS or to reduce the risk of being diagnosed with an invasive breast cancer.

Instead, complementary and alternative medicine treatments may help you cope with your diagnosis and the side effects of your treatment, such as distress. If you're distressed, you may have difficulty sleeping and find yourself constantly thinking about your diagnosis. You may feel angry or sad. Talk about your feelings with your doctor. Your doctor may have some strategies to help alleviate your symptoms. Combined with your doctor's recommendations, complementary and alternative medicine treatments may also help. Examples include:

- Art therapy
- Exercise
- Meditation
- Music therapy
- Relaxation exercises
- Spirituality

Coping and support

A diagnosis of DCIS can be overwhelming and frightening. To better cope with your diagnosis, it may be helpful to:

- **Learn enough about DCIS to make decisions about your care.** Ask your doctor questions about your diagnosis and your pathology results. Use this information to research your treatment options. Look to reputable sources of information, such as the National Cancer Institute, to find out more. This may help you feel more confident as you make choices about your care.
- **Get support when needed.** Don't be afraid to ask for help or to turn to a trusted friend when you need to share your feelings and concerns.
- Talk with a counselor or medical social worker if you need a more objective listener. Join a support group — in your community or online — of women going through a situation similar to yours.
- **Control what you can about your health.** Make healthy changes to your lifestyle, so you can feel your best. Choose a healthy diet that focuses on fruits, vegetables and whole grains. Try to be active for 30 minutes most days of the week. Get enough sleep each night so that you wake feeling rested. Find ways to cope with stress in your life.

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<https://www.mayoclinic.org/diseases-conditions/dcis/diagnosis-treatment/drc-20371895>

DCIS: You've got a good outcome so why are you crying?

Janine Porter-Steele RN PhD, Clinical Nurse Manager,
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Janine Porter-Steele

Ductal carcinoma in situ (DCIS) is a non-invasive and sometimes described as a pre-invasive or early breast cancer. DCIS occurs when some of the cells that line a group of milk ducts within the breast have started to become cancer cells. As these cells are contained within the ducts (in situ) and have not spread into the surrounding breast tissue, there is very little chance of the cells spreading into the lymph nodes or anywhere else in the body¹.

Nearly all women who are diagnosed with DCIS will be advised to have some treatment because at this point it is not possible to predict who may go on to develop invasive breast cancer where cells have moved on beyond the ducts. The goal of DCIS treatment is to ensure the abnormal cells in the milk ducts do not spread to the breast tissue and become invasive breast cancer, and to prevent it from returning later¹. Research has shown there is an increased risk of this happening².

Women sometimes find DCIS to be a complex, confusing and often overwhelming diagnosis because of the different terms used to describe it (pre-cancerous, pre-invasive, non-invasive, early breast cancer)³. Plus, despite this terminology and the fact that they are most likely to be asymptomatic in that those diagnosed with it do not experience a lump in their breast, discharge, visible breast changes or discomfort, the treatment options offered are similar to those offered to women with invasive breast cancer. These involve surgery to the breast (lumpectomy, mastectomy with or without breast reconstruction) and potentially other forms of treatment (radiotherapy and hormonal therapies^{1,2}). For many women this seems at odds with a diagnosis of early-stage breast cancer.

Some women have said that, although they felt shocked and frightened to be diagnosed with DCIS, they also felt guilty because it was "only" DCIS and not invasive breast cancer. As a result, many women find it difficult to join support groups because they feel they haven't had to undergo chemotherapy and so shouldn't be expressing concerns or feelings when others seem to be "doing it so much harder". They also feel they are taking up a place or the health professional's time when they have "early, curable" breast cancer and others might not be able to expect such a positive outcome.

Yet women who have been treated for DCIS have similar concerns and will face similar recovery challenges as those women diagnosed with invasive breast cancer. The scarring from a lumpectomy or mastectomy, the lack of sensation or concerns about visual expectations from reconstruction or skin damage from radiotherapy plus body changes experienced from potential hormonal therapies (if prescribed) can have an enormous effect on sexuality, body image, self-esteem and self-confidence.

Emotional wellbeing can be further adversely affected through fear of DCIS coming back and of developing invasive breast cancer. Added to this, challenges associated with the financial costs of being diagnosed, trying to cope with other life challenges, or lacking in support systems through personal and/or geographical isolation are no different for those with DCIS and those with invasive breast cancer. Anxiety, depression, and guilt are some of the significant emotional effects reported by women who have had DCIS.

Because of this, it is important for women to feel they can and should access support through their health professionals and peer support connections. Facilitated peer support through groups or on-line and personal connections can provide emotional support, practical help and advice from others who have lived through similar situations and allow a woman with DCIS to find a safe place for sharing concerns, asking questions, and gaining confidence to face the future. In many countries a breast care nurse (BCN) or cancer care nurse is available to discuss any concerns. BCNs are highly trained and specialist individuals who provide continuity of care and aim to develop a close therapeutic relationship with each woman diagnosed with breast cancer and her family to help support them from

diagnosis all through the treatment process⁴. They recognise that these concerns are as important for women with DCIS as any other breast cancer diagnosis. BCNs provide evidence-based care that is tailored very much to the individual and aims to be holistic and responsive to their needs⁴. Help can be given with decision making to enable the patient to take an active part in their treatment. BCNs give practical support in managing side effects of treatment. They also promote recommended lifestyle and behavioural changes in relation to exercise, diet and alcohol consumption and managing late and long-term side effects of treatment. BCNs endeavour to provide emotional support from diagnosis, throughout treatment and beyond, supporting not only the woman but also her family. Support on the impact on a woman's body image, self-esteem, fertility, menopausal side effects, and keeping intimacy is woven throughout the continuum of care. The BCN also supplies support to manage the complexities of a breast cancer diagnosis in a way that is appropriate to their individual and cultural needs.

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And now for something new...DCISionRT®

Janine Porter-Steele RN PhD, *Clinical Nurse Manager,*
The Wesley Hospital Choices Cancer Support Centre, Brisbane, Australia

A new test is being made available in Australia and some other countries for women who have been diagnosed with Ductal Carcinoma in Situ (DCIS) and have had conservative surgery (lumpectomy).

The test called DCISionRT® is a risk assessment tool. It can help with making treatment decisions by assessing the risk of DCIS returning or spreading in the next 10 years in the recently operated on breast. It also evaluates the impact of radiotherapy in reducing this risk.

There is no need for another biopsy, as the one taken during surgery is used and then assessed for 7 particular bio markers in the cell. The result of the test is considered alongside 4 other known risk factors, such as age, whether the breast cancer was found by mammogram or through a clinical examination, the size and extent of the tumour and whether the margins around the tumour were clear. A report is prepared showing whether someone is at a low or increased risk of their cancer returning and the value of radiation treatment for each individual person.

This is important because it is allowing for more personalised treatment and a “not one size fits all approach”. Whilst this test is not available everywhere in the world, it is valuable progress in understanding DCIS and hopefully will become more accessible and available elsewhere in the near future.

The DCISionRT® test is currently available through Genesis Care Australia partnering with PreludeDX more information can be found on the DCISionRT® website

https://www.genescare.com/au/treatment/cancer/dcisionrt/?gclid=EAlaQobChMI4fPX4fuD-AIVxZJmAh2d3g0qEAAYASAAEgKCxfD_BwE

<https://preludedx.com/patients/>

When women start questioning: An examination of issues related to Ductal Carcinoma in Situ (DCIS)

Rama Sivaram, Nag Foundation; KEM Hospital Research Centre, Pune
Pune, India



Rama Sivaram

A diagnosis of breast cancer is enough to arouse a woman's fear and emotions, be it DCIS stage 0/1 or any other stage. A palpable lump she has felt, a non-palpable lump seen on an ultrasound or mammography, or a suspicious micro calcification detected on a routine mammography screening all create mixed and confounding responses in women I have counselled and met. Practicing oncologists in integrated cancer centers and tertiary speciality hospitals respond to DCIS with clarity with their accrued experiences, up to date knowledge, and team work. This enables appropriate diagnosis and management based on personalized risk benefit ratio for every woman and her type of DCIS.

The US's National Cancer Institute defines DCIS as:

A condition in which abnormal cells are found in the lining of a breast duct. The abnormal cells have not spread outside the duct to other tissues in the breast. In some cases, ductal carcinoma in situ may become invasive breast cancer and spread to other tissues. At this time, there is no way to know which abnormal cells could become invasive. Also called DCIS and intraductal breast carcinoma.

The caveat here is the phrase "may become invasive – a potentially invasive neoplasm . . . ' The incidence of this usually clinically silent condition has risen in the past few decades due to widespread screening and diagnostic mammography, with final diagnosis confirmed by biopsy."¹ The diagnosis is perplexing to both patient and physicians. The patient must deal with her emotions, fears, doubts about her DCIS status, and faith in her doctor; the oncologist must balance the ethical and clinical options of undertreatment or overkill. To add to the problem is that, in India, cancer is still in a socio-cultural limbo, with lingering views from the last quarter of the 20th century that cancer means do or die, mastectomy or death.

In my country, symptomatic stage 2 and 3 presentations are more common than DCIS, so it is easy for me to recall the perspectives and questions of the few DCIS patients with whom I have met.

Here are examples of what they asked:

- If there are only few dots here and there, how do we know it is cancer and why treat it?
- Can I wait and watch and do nothing about it?
- Why did my doctor say come back for another mammogram after three months?
- Is a microcalcification a cancer?
- Why does it say BI-RADS 2 or 4? What does it mean?
- I can understand a lump, but dots? Why have surgery, chemo, and radiation for speckles?
- Why only surgery and radiation?
- Why 5 years of tamoxifen? Won't it harm?
- Why different treatments for them and me?
- Am I to blame for rejecting chemo and radiation?
- I did everything the doctor said and here I am back with a recurrence?

Being diagnosed with DCIS is full of "ifs" and "buts," comparing one's own diagnosis with other women's breast cancers, feeling confused with lack of awareness of types and subtypes, and struggling to maintain confidence in doctors and treatment plans. This brings home the fact that there are many gaps in the understanding and communication of a DCIS diagnosis. To effectively address issues related to DCIS,

the following are necessary:

- **Well researched, evidence based, uniform, diagnostic and treatment protocols.** Do we have this? YES, we do! The National Cancer Grid Breast Cancer Management Guidelines include a well-studied and planned algorithm. Evaluation mandates a triple test comprised of a clinical examination by an experienced clinician, imaging of both breasts with mammography and or ultrasound and in indeterminate cases an MRI as appropriate, and histopathology (Core biopsy preferred, or FNAC). An incisional biopsy may be considered in exceptional cases.² The Guidelines further define a step by step approach to evaluation and treatment of DCIS. With respect to low- and middle-resource countries, both diagnostics and treatment protocols are accounted for on a carefully drawn eligibility criteria so that none go without care.
- **Robust education for clinicians practicing cancer care in private or public institutions such as hospitals and laboratories.** Health care in India is a mix of public and private partnerships that range from good to not so good. The aim is to fill in the gaps and make health care for all available. However, when it comes to specialty and multi-modal care required for cancer, there are two sides of the coin: one side enhances advanced diagnostics and increased access to tertiary care, but the other side is out of pocket expenditures of 65% or more, inequity or disparity, and smaller private

clinics and laboratories with insufficient facilities and oncology clinicians who are neither skilled nor experienced. At such facilities, a surgery or excision and chemotherapy with or without histopathology is the best women with DCIS will get. Microcalcifications are simply not addressed. It is essential to improve the situation with sufficient facilities, training, regulation, monitoring, mandatory certifications, etc. Because DCIS has the reputation of being stealthy, it requires more mature and experienced handling. Academic communication is as important as communicating with patients. The point that needs to be driven home is that there are still clinicians who have not been trained in the work up and management approaches which can add human error to the disease's own biology and thus increase the chance of a DCIS becoming a potentially infiltrating or invasive carcinoma.

• **Supportive education and counselling for women and caregivers.** Women by far are still passive observers of their own treatment. Unless a patient learns about her own breast and her own disease and questions her diagnosis and treatment, she will always remain in fear and doubt, blame herself and her doctor, in effect consenting to be wrecked because of the silence. Patients who are passive observers put too much expectation on oncologists who are tirelessly working with patient overload to answer every question about DCIS – more so when the report carries microcalcifications, low grade, high grade etc, which have the potential to cause havoc at a future point of time. Supportive care in the form of counselling and education plays an important role here. The scene is changing slowly, as more and more patient advocacy groups talk about their lived and living experiences. This needs to be done in the right space and within an acceptable time frame. Those providing counselling and education must have special communication skills and

factual information that can be explained in easy to understand terms. This becomes more relevant in DCIS, which raises so many questions, being partly occult and partly plastic. It must be gently disclosed that every need and expectations cannot be met, and the oncologist's goal with treatment is long-time survival and prevention of a recurrence and other collateral damages. Emotional distress and psycho-social impact can also be effectively addressed. Psychologist Rebecca D'Souza observes a common factor to all breast cancers as a whole is that the psychosocial impact is the same, and knowing that the problem is being treated is important. Encouraging patients to comply with follow-up care recommendations is crucial in preventing DCIS from becoming invasive and in detecting potential recurrences or new primaries.

I would like to thank the oncologists who answered my questions promptly and patiently:

- Dr. Shona Nag, Director Oncology, Sahyadri Group of Hospitals Pune. From being my medical oncologist in 2004 she has mentored me without our knowing over the years even today.
- Dr. Sanjay, MH Radiation Oncologist, Sahyadri Group of Hospitals Pune
- Dr. Shriniwas Kulkarni, Medical Oncologist, Sahyadri Group of Hospitals Pune
- Dr Anupama Mane- Breast Surgeon, Ruby Hall and at multi-speciality hospitals in Pune
- Dr Vikram Maiyya- Radiation Oncologist, HCG Bangalore
- Ms. Rebecca D' Souza, Psychologist Nag Foundation
- Dr. Anupama Mane-Breast Surgeon, Ruby Hall and at multi-specialty hospitals in Pune

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Personal
story

Personal story: An examination of issues related to DCIS

By Janet Ladd, PCC, Maryland, USA



"Look at the dust that's riddled throughout my films. They really need to clean their equipment," I thought to myself as I sat in a small waiting room reviewing my mammogram images while waiting for the radiologist to join me. I was ushered into the room shortly after my first-ever mammogram. Looking back at that moment, I realize how naïve and unprepared I was for the journey ahead. The "dust" I was seeing was later diagnosed as ductal carcinoma in situ (DCIS). The radiologist explained that DCIS is the presence of abnormal cells inside a milk duct in the breast. Also called "stage 0 breast cancer," I remember questioning the doctor skeptically whether I had cancer at all! I later understood that, in many instances, the cells that line the milk ducts have changed to cancer cells but, because they have not spread through the walls of the ducts into surrounding breast tissue, it's considered "non-invasive." I was encouraged to schedule an appointment with an oncologist as quickly as possible. Additional tests would be needed. I recall feeling numb as I left my mammogram appointment, still in disbelief that a cancer diagnosis was possible.

As the weeks passed, things became all too real. I submerged myself in research, learning as much as possible about DCIS. After the results of a stereotactic breast biopsy (which is used by a specially-trained radiologist to remove tissue samples to assess breast abnormalities) confirmed the presence of cancer cells with some micro-invasion of the cancer into surrounding tissue, I carefully crafted a message to break the news to my young children, parents, family and friends. I was torn – how do I communicate this

disease to a six- and nine-year old when I hardly understood it myself! How do I answer their questions about the future when the uncertainty kept me up at night? I learned that the DCIS was present in three quadrants of my right breast. The first surgeon with whom I consulted indicated I could have good results with a lumpectomy. Knowing the importance of a second opinion, and blessed to live near some of the best medical institutions in the world, I decided to consult with the Director of a local accredited Breast Cancer Center, who discussed treatment options, including the pros and cons of a lumpectomy v. mastectomy. Because the cancer had spread outside of my milk ducts, the surgeon encouraged me to consider a mastectomy over lumpectomy procedure.

After much deliberation, I decided a single mastectomy was the best choice for me. Because of the extensiveness of the DCIS, I was concerned that a lumpectomy would leave my breast distorted. And, my hope was that removing the entire breast would minimize the possibility of recurrence. Having made that decision, I now needed to consider reconstruction alternatives. As a young wife, mother, and busy professional, I knew that breast reconstruction would help me move beyond my cancer diagnosis. This decision also required extensive research, finding that physicians seemed to promote the procedures with which they had most comfort. Once again, I was blessed to find a surgeon with expertise in the DIEP flap procedure. DIEP, Deep Inferior Epigastric Perforator, was – at that time – a relatively new procedure. It allowed me to use skin, fat, and blood vessels from my abdomen to reconstruct my breast v. an implant.

Although a more extensive procedure than implants or the TRAM reconstruction alternatives, I was pleased I could have the reconstructive breast surgery at the time of my mastectomy. And, compared to the TRAM procedure, DIEP does not impact the abdominal muscles. DIEP also alleviated concerns I had about the risks that come with artificial implants.

In going through my cancer experience, I came to realize how delicate and uncertain life is. I was also reminded how important it is to have the support of family, friends, and caregivers. I also came to understand that recovery is both a physical and emotional process. I believe that in the "quiet of recovery" (after the whirlwind of activity surrounding the detection and treatment of the cancer itself), my emotions caught up with the rest of me. While still positive and – especially after hearing good news from the pathology report, which indicated that my surgery was successful in removing my cancer – very, very thankful, I realized that there weren't any detours along the journey. I had to be patient and accept both my feelings and physical limitations for what they were at the moment. As one fellow breast cancer survivor and Reach to Recovery volunteer instructed me, "You have to be." Sixteen years after my initial cancer diagnosis, this advice still resonates, not only for working through cancer but in navigating life's inevitable ups and downs. I am grateful to the Reach to Recovery organization and have been pleased to volunteer my own support to those traveling through their own breast cancer journeys.

Personal story

Four perspectives on DCIS from Portugal

By Lurdes Cordeiro, Celeste Delgadinho, Carolina Negreiros, and Conceição Couto

Four women from Portugal, each with different life stories, are united by the desire to minimize the damage to other women caused by a cancer diagnosis. All of these women were diagnosed with Ductal Carcinoma In Situ (DCIS), and today they are all volunteers with the Win and Live Movement of the Portuguese League against Cancer.

After overcoming the most difficult moments, they all felt the same need to contribute to the well-being of other women going through what they went through. They found the ability to do just that with the Win and Live Movement.



Win and Live Movement

Carolina Negreiros



Carolina started her surveillance before she was 50 because she had a family history of cancer. In 1990, when she was 52, a change appeared in a lymph node of the axilla and a biopsy revealed cells suggestive of malignancy. Carolina had a mastectomy with axillary dissection and 10 years of hormone therapy.

In Carolina's words: When we receive the diagnosis we don't want to believe it, it seems like a nightmare! We want to be told that it's not true! We have a terrible fear and the surgery appears as a liberation.

Fear is a terrible thing! Fear, ignorance and negligence are cancer's greatest friends!

When we get home, we are confronted with new

situations. Looking at our body in the hospital in that small mirror above the washbasin, still with bandages, is nothing compared to seeing our full-body image later in a mirror.

It was not easy, I was used to my old image and it was difficult to adjust to the new one. I had liked my body! But now what? Thirty-two years ago reconstruction was not very common! It was important for me to hear from my husband, "Why do you only think about the scar, if for me you are a whole!" That sentence made me rethink my attitude!

It is very important to think of ourselves as a whole, to value what we have and not what we don't have.

I emphasize here the importance of prevention and early diagnosis, otherwise I might not be here today!

Conceição Couto

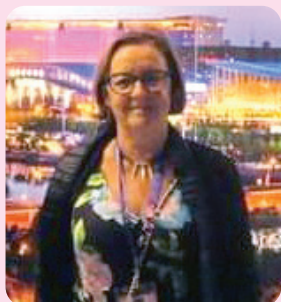


Conceição was diagnosed with DCIS in 2018. She underwent a breast-conserving surgery, 4 treatments of immunotherapy and 20 sessions of radiotherapy.

In Conceição's words: All my life I feared I would develop breast cancer like my mother, so I began my screenings at a very young age. My mother was diagnosed with cancer when she was just 35, after a pregnancy, and she died at the age of 37, when

I was 6. I knew my risk for breast cancer was high because I had a strong history of breast cancer in my family. Although my breast cancer was diagnosed at an early stage, it was very difficult for me. I have faith and I'm sure I'm going to beat this challenge. Currently, I volunteer to help people like me who suffer from cancer. I feel happy and confident doing this and I know prevention is the best option.

Lurdes Cordeiro



Diagnosed with DCIS in 1983, Lurdes had a total right mastectomy. Twenty years later, in 1983 she had reconstruction surgery using muscles from the stomach.

In Lurdes's word: Things happened so quickly that I had no time to think about what was happening to me. It was surreal. When I recovered from surgery and was informed that my breast had been removed, I felt as if an earthquake had happened in my life. My mind went black. I could not see any light. My thoughts were just as follows: I would not survive, my husband of course would reject me and ask for a divorce, my children would grow up without me. Everyone around me was sad; only my mother looked strong and gave me hope.

After surgery, for three days I experienced this horror. But then one afternoon, a nurse told me that I would get a visit from a volunteer from the Win and Live Movement. Her name was Maria Augusta Amado, and she had experienced a similar situation.

I have no words to describe what went on during that one-hour visit. The experience was so strong and

successful that after 39 years I can still remember it as if it happened yesterday.

During our face to face meeting it was hard to believe that she, also, was missing a breast.

She told me, "It is not the end of the world! If by now your marriage is good, it will go on or it will still improve. Without tiring yourself, you will gradually achieve performance in all tasks. A provisional prosthesis of hypoallergenic cotton and after some time a silicone prosthesis will return your silhouette." She spoke such simple words, but what she said radically changed my attitude. I stopped seeing black, not even seeing grey, but a deeply brilliant white. And this was only the first meeting!

Maria and I became close friends, and she recognized in me the qualities that make a good peer support volunteer. She trained me to volunteer with the Win and Live Movement. That lady of small stature, but with immense talent as a volunteer, was the founder of the Win and Live Movement in Porto (Portugal). She passed away on 29th August 2010, but she will be in my mind and heart forever.

Celeste Delgadinho



Celeste's DCIS was found in 2017 during a routine ecography, although nothing had been felt or revealed either by palpation or mammography. Celeste had a total left breast mastectomy with sentinel ganglion biopsy. She is currently undergoing hormonal therapy

In Celeste's words: I started breast cancer screening at age 40, even though I had no signs or symptoms, because my mother had suffered from this disease and died at the age of 60.

The success of the treatment of my carcinoma is due to the fact that it was diagnosed at an early stage. I must add that, on an emotional level, my experience had a strong impact on my self-image and even on my life path. The total support of my husband,

which was (and still is) fundamental, as well as the psychological support I sought, helped me achieve a better understanding and acceptance of the disease and return to normality.

In the Win and Live Movement, volunteers share the fears they lived with and overcame with women now living through similar situations. A woman who meets another woman who has gone through the same situation feels understood, supported, and safe. She is able to share her fears and even learn other ways to cope with the disease. What in many cases would be an individual experience becomes, through sharing and emotional support, easier to overcome and makes women feel better.

Personal
story

A view from a survivor in Tasmania

By Mandy Forteath, OAM, Launceston, Tasmania, Australia



“ I AM GRATEFUL FOR EVERY DAY, MY FAMILY, MY FRIENDS, BCNA, AND THE OPPORTUNITIES AFFORDED TO ME OVER THESE PAST 18 YEARS. ”

In May 2004, at the age of 52, I was diagnosed with Invasive Ductal Carcinoma in a background of Ductal Carcinoma in Situ in two different sites on my left breast. There was also metastatic adenocarcinoma involving my axillary lymph nodes, so I had no choice but to have a radical mastectomy followed by chemotherapy treatment. Both the DCIS and invasive carcinoma were shown to be both Oestrogen and Progesterone receptor positive, which then put me on the treatment path of ten years on Tamoxifen.

I was in shock at the moment the doctor showed me the scans and pointed out the cancers. I felt as if I was a cartoon character, standing in a tunnel on railroad lines when the huge black train hit me, shoving my core behind me into the darkness.

I could feel no lumps, had breast fed my children, had no family history, had never smoked, and hardly drank any alcohol. I knew nobody who had undergone a similar experience and, living in a regional city in Tasmania, the island south of the Australian mainland, felt quite alone and frightened. With an island population of 500,000 people, we were lucky to have a specialised cancer centre a short distance away from our home, and I placed my body and faith in the experts who worked there.

Quite early on I experienced lymphoedema of the left arm, so sought out practitioners who could assist me in managing this ailment. To this day, I regularly go to a pool to do exercises, attend weekly tai chi sessions, and walk as much as I can (with aging knees!).

Once chemotherapy was completed, my hair grew back, and I resumed my new normal life, I found that peer support was missing. Although everyone was caring and kind, if they had not heard those words “I am sorry, but you have breast cancer” their comprehension of my life seemed shallow to me. Friends and colleagues assumed that now that I *looked* the same as before I was the same as before, but every single cancer patient in the world will tell you that the diagnosis changes the world instantly. Our bodies have let us down and we cannot trust them again.

I was hugely fortunate to link into Breast Cancer Network Australia (BCNA), which was started by a sole woman who had experienced feelings similar to mine. This group highlights the woman, not the disease, as it supports, informs, represents, and connects Australians affected by breast cancer. I chose to become a voluntary Consumer Liaison for BCNA in order

to be trained so that I could spread the word about BCNA and later trained to be a volunteer Consumer Representative as well. This role afforded me the wonderful experience of joining in on research boards and projects as a consumer, thus adding survivor voices in real and meaningful dialogue. I followed this by coordinating a local support group which met monthly, as well as accepting the opportunity of training as a voluntary Consumer Advocate for Breast Cancer Trials.

These roles have informed and educated me on the future ahead for those who will be diagnosed with breast cancer. New results from extensive international trials are being published regularly and every time I have returned from a conference, I have been buoyed by the information supplied by the expert scientists.

I feel that my cancer diagnosis has given me a new outlook on life. I have met so many wonderful women, all wanting to “get on with life” yet, at the same time, be aware and informed of what is happening in the breast cancer world. I am grateful for every day, my family, my friends, BCNA, and the opportunities afforded to me over these past 18 years.

Personal story

Cancer is tough, but we are tougher!

By Mwende Mutiso, Kenya



“

KEEP CHASING
HOPE! CANCER IS
TOUGH, BUT WE
ARE TOUGHER!

”

My name is Mwende Mutiso. I am 29-years old and I am a metastatic breast cancer survivor.

Breast cancer was not a topic I was conversant with until 2014, when I attended a medical camp organized by Resource Center for Women and Girls and was taught how to do breast self-examinations by a mentor, Catherine Ngaracu, breast cancer survivor. Little did I know that this would in effect save my life.

Almost two years down the line, I was diagnosed with stage 0 breast cancer (Ductal Carcinoma In situ). I had a single mastectomy in September 2016, after which I was declared cancer free and put on medication for 5 years.

Towards the end of 2019, I noticed slightly swollen lymph nodes in my neck and, after a series of tests, I got devastating news - the cancer was back. This time spreading to several lymph nodes and one of my lungs. I was diagnosed with Metastatic Ductal Carcinoma (Stage 4 Breast cancer).

During my first oncology appointment, the doctor told me that I had only one year to live since the cancer was not only

aggressive but it had advanced. At first, I contemplated not doing the treatment as I didn't want to spend my last year being sickly, not to mention the financial constraint which the treatment was going to have on me and my family. Cancer treatment is ridiculously expensive.

But, due to the strong support system I have, I decided to do the treatment. Thanks to the mental and financial help from my family, friends, and colleagues, I began the treatment, which consisted of chemotherapy and hormonal therapy.

The treatment worked better than anticipated. All tumors resolved and the one in my lung significantly reduced in size.

With continued treatment, in July 2021 I was declared to have “No Evidence of Disease.” All along, I had been preparing to climb Mt. Kenya to tick off an item from my long bucket list. I am happy to say that I achieved this goal, and have hiked Mt. Kilimanjaro as well! This was made possible through the support of Kilele Health Association, which is a group of care givers and survivors who hike for a purpose: to create awareness and to show there's life beyond a cancer diagnosis.

Living with Advanced Breast Cancer has its challenges; however, this diagnosis has taught me to live intentionally, to value the little things, and to cherish every moment. Most importantly, it has taught me to live life one day at a time and to have hope for a brighter tomorrow.

Creating breast cancer awareness has been liberating. Above all, inspiring people and being inspired by them has been a source of healing and connecting with an even bigger support system.

Keep chasing hope! Cancer is tough, but we are tougher!

Personal
story

A note from a DCIS survivor

By Christine Annathasia Trini, Jakarta, Indonesia



“

ON THIS OCCASION, I WOULD LIKE TO TELL ALL WOMEN TO LOVE AND CARE FOR THEMSELVES BY GOING FOR THE ROUTINE CHECK UPS. NEVER BE AFRAID TO GET MEDICAL TREATMENT.

”

Unsteady. Feeling like the world is collapsing. That's how I felt when the oncologist stood before me and told me the results of the pathology report from surgery I'd undergone 10 days earlier. "Breast cancer – DCIS."

I wondered confusedly: what *is* DCIS? How can I have breast cancer when I'm just 35 years old? I tried to stay calm and asked the doctor to explain. I learned that DCIS is a cancer that has formed but is still contained and has not metastasized. That's when my cancer journey began.

It was late 2009, and not many hospitals in Jakarta had radiotherapy facilities. Fortunately, Cipto Mangunkusomo Hospital

(RSCM) did and I was directed there. I underwent 30 sessions of radiation, one every week day for 6 weeks. There were blood tests, a thorax scan, a bone scan, and an Immunohistochemistry examination. Thankfully, I managed to keep my spirits high as I focused on my full recovery!

When my course of radiation was finished, I was sent to Dr. Evert Poetiray, a breast cancer specialist, who performed my routine check ups for three years. Since 2012, I have been getting my annual examinations at the Indonesia Cancer Foundation (ICF). These involve mammography, abdominal and thorax scans, and blood tests. I value these

annual routine examinations because they reassure me that my body is healthy. I also joined ICF's survivor group in 2013 and am still a member today.

On this occasion, I would like to tell all women to love and care for themselves by going for the routine check ups. Never be afraid to get medical treatment. I am a breast cancer survivor since 2009, and I'd like to keep it that way!

#MyJourneyWithDCIS

Personal
story

The importance of supporting others

By Nitta Suzanna, Jakarta, Indonesia



“

TOGETHER, ALL OF US CAN HELP AND IMPROVE THE LIVES OF MANY MORE OF OUR SISTERS AND LIVE LONG, PROSPEROUS, AND HEALTHY LIVES.

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In November 2015, my life completely changed forever. I found myself in a situation with which I had no experience. I was scared, I felt overwhelmed, I needed information, I needed recommendations, and I needed a lot of help to act and to act fast.

It is now more than six and a half years later and I am a passionate and proud breast cancer survivor. My journey has inspired me to dedicate my time to help my sisters who find themselves in the same situation as I did. I want to help and inform and talk to as many women as I can. I don't want any one of us to wait until a point when treatment becomes a challenge. I want all of my sisters to act quickly, all of us together with information, support, and a strong

network of friends and family. This way we can help many more women fight this disease.

My name is Nitta Suzanna and I am a proud member and advocate of the Indonesian Breast Cancer Foundation (YKPI). Its strong support of me during my journey is one of the key reasons why I am a breast cancer survivor.

The Indonesian Breast Cancer Foundation is here for all of us, and I manage the call “Hot Line.” I am directly in contact on the front line to help my sisters and also their families. Together, all of us can help and improve the lives of many more of our sisters and live long, prosperous, and healthy lives.

Enchiladas rojas

Global
Kitchen

SERVINGS: 6



Ingredients:

For red sauce:

- 3 cups of tomato puree
- 1 small onion, finely chopped
- 1 garlic clove, chopped
- 2 green chilis
- 2 tablespoons vegetable oil
- 1 cup of sour cream
- Salt and pepper

For the enchiladas:

- 12 corn tortillas
- 2 cups of grated cheese or shredded chicken (cooked)
- Oil for frying

Directions:

For the red sauce:

Add the onion, garlic, chilis, and tomato puree to blender and blend until smooth. Add salt and pepper to taste.

Heat the oil in a frying pan and pour the mixture into it. Cook over medium heat until the sauce is thick. Set aside.

To assemble:

Heat the oil and fry the tortillas, for about 30 seconds on each side. Drain on paper towels.

Dip the tortillas in the tomato sauce one by one to coat

Fill each tortilla with cheese or shredded chicken and roll to seal. Place them in an oven proof dish. Pour the remaining sauce over the rolled tortillas and add the sour cream on top. Sprinkle with the remaining cheese. Heat at 350 degrees in a pre-heated oven for about 10 minutes. Serve soon, as they go soggy if left to stand.

Chiles en Nogada

Global
Kitchen

Chiles en Nogada is an authentic Mexican recipe. It is usually reserved for holidays or other special occasions because it can be a bit expensive for many families.

Many people think of spice when they hear the word “chile,” but in this case that isn’t necessarily accurate. Poblano chiles, which are a little bit spicy, are used for this recipe. However, after roasting them and removing the skin and seeds, they become much milder. Further, combined with the fruit and meat filling and the creamy nut-based salsa, this recipe is not very spicy at all! The combination of flavors makes for a palate-pleasing meal.

Chiles en nogada is a great representative of Mexican culture because of the colors of the traditional ingredients. The poblano chiles are green, the creamy salsa is white, and it is often adorned with pomegranate seeds which are red. Those are the colors of the Mexican flag.



SERVINGS: 10

Ingredients:

For the base:

10 Poblano peppers roasted,
with skin and seeds removed

For the filling:

¼ lb ground beef
¼ lb ground pork
1 cup tomato sauce
1 white onion, diced
5 cloves garlic
¼ tsp ground cinnamon
3 black peppercorns
¼ tsp ground cloves
½ tsp dried thyme
1 tsp salt
1 tsp sugar
½ large apple, diced
½ pear, diced
1 peach, diced
½ ripe plantain, diced
¼ cup raisins
1 tsp olive oil

For the Salsa de Nagada:

2 cups walnuts or almonds, skins removed
½ cup milk
3 oz goat cheese or cream cheese
1 tsp sugar
Salt to taste

For the garnish:

Parsley, chopped
Pomegranate seeds

Directions:

For the Salsa de Nogada

Start by putting the almonds or walnuts in hot water for about 20 minutes. This will make it easier to remove the skins, resulting in a white salsa.

Once you have removed the skins, put the almonds or walnuts in cool water for 15 more minutes.

Put the almonds or walnuts and the rest of the salsa ingredients in a blender and blend until smooth. Remove from blender and set aside.

For the filling

Start by sauteeing half of the onion, the peppercorns, and the garlic in a frying pan with the olive oil for a few minutes.

Put the onion mixture and tomato sauce, thyme, and cloves in blender and blend until smooth. Set mixture aside.

In the same pan in which you sauteed the onion, peppercorns, and garlic, add the rest of the onion, the ground meat, and salt and cook until the meat is cooked through.

Add the fruits and cook for an additional 5 minutes.

Add the cinnamon and sugar, stir, and cook for 3 more minutes over medium-low heat.

Add the tomato sauce mixture from steps 1 and 2 above to the pan and let simmer until almost all of the liquid has evaporated. The meat should not be dry, but it should not be too watery because that would make it harder to fill the poblano peppers.

To assemble

Roast the poblano peppers, then clean by cutting them in half and removing the skin and seeds.

Add some of the meat and salsa to each of the halves. You can use toothpicks to close the halves back up if desired.

Smother in remaining salsa and top with parsley and pomegranate seeds.