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Fatal Flaw In Breast Cancer Screening



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Impact of Dense Breast Tissue On Reliability Of Mammograms

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The internet and social media have transformed our lives. They have literally opened up a global connection to those with similar interests and passions. In my focused world of patient advocacy for breast health, I meet innumerable women, fervent in their yearly breast cancer screening, yet diagnosed with a missed, delayed and advanced stage cancer because of their dense breast tissue. Like me, these women never knew about the impact of dense breast tissue on the reliability of their mammogram until after their diagnosis. Our mission is to correct this fatal flaw in breast cancer screening.

Through a quick internet search for information about dense breast tissue, these 'strangers' quickly become my fast friends. I often kid that AreYouDense.org and AreYouDenseAdvocacy.org, the websites of our two nonprofit organisations, are akin to an online-dating service, uniting me with breast cancer patients, stunned by their laterstage cancers, in spite of never missing a mammography appointment. These encounters lead to a relationship cultivated by emails, texts and online messaging.

Through Facebook, I remotely get introduced to their kids, grandkids and pets, often commenting on their family's memorable moments and encouraging them as they progress with their breast cancer treatment. As with online dating, at times we advance the relationship by communicating by phone and on several occasions meet in person. These women become my extended family. Relationships, which were birthed based on our common bond of breast cancer, develop into a heartfelt friendship.

Bumpy Road of Patient Advocacy and Breast Health

Upon my advanced stage cancer diagnosis in 2004, after never missing an annual mammography appointment, I asked my 'team' of doctors as to why my 11 years of normal mammograms did not find my cancer. I was stunned by each of their responses that my dense breast tissue, which I was unaware of, masked my cancer for years and that mammograms are limited in finding cancers in dense breasts. The non-nonchalant responses from my health care team and their refusal to disclose this 'dense' information to their patients as part of their mammography report, led me to travel the bumpy and unpaved road of patient advocacy and breast health. A decade of research existed at the time of my diagnosis on the limitations of mammograms in women with dense breast tissue and more than two decades of research on the causal risk of dense breast tissue.

My desire was to expose the secret of dense breast tissue, taking this information from the scientific journals to the examining room.

The Immense Reach of Social Media

Social media have brought together a community of breast health advocates, breast cancer survivors, and healthcare providers, to communicate about the many aspects of breast cancer such as prevention, risks, screening, treatments, and promising research for a cure. Open 24 hours, within seconds of breast cancer survivors' posts about side effects from treatment, decisions about surgery and their most intimate anxieties and fears, the cheer-leading team of survivors, caregivers, and health care providers intervene. My advocacy work and our immense reach through social media, give me the opportunity to console a sister or brother, to offer hope to them and their families as they 'live' with a breast cancer diagnosis.

In the United States, breast cancer is the second leading cause of cancer deaths in women and the leading cause of premature mortality. Whether from my local community support group or through the infinite bond of social media, I have experienced much gratitude hanging out with my breast cancer friends. Not thankful for our diagnosis, but because of the fragility of cancer, we have a heightened gratitude for each day. Too many of us can check all the boxes for the prevention measures we adhered to - no smoking, maintaining a healthy weight and diet, being physically active and never missing our yearly mammography screening. Consequently, I experience grief all too often.

My global connections with friends with a breast cancer diagnosis, connect me with women whose cancer had metastasised upon diagnosis. Their deaths hit hard. Like the death of President Kennedy when I was in grammar school, I can recall the exact time and place when I received notice about one of my friends' passing.

Often the notices are through social media. Having experienced more deaths than I am prepared for, I often think of our first-responders and hospice health-care providers, where death becomes commonplace and wonder how they cope with their frequent grief.

The lives and deaths of my extended newfound family motivate me as I advocate for our mission to eliminate grief of a loved one dying prematurely from this disease. The complexity of breast cancer biology tells us that even with an early diagnosis, the disease can progress and kill. However, research also concludes that early detection still matters. Tumour size and nodal status still have a significant and major influence, independent of tumour biology, in the current era of more conservative surgery and more effective systemic adjuvant therapies.

Advocating for Density Reporting and Education

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While my heart and soul grieve the death of friends from breast cancer, it also motivates me to continue to advocate for density reporting and education and access to multimodal screening to reduce advanced disease and premature death from breast cancer.

Follow Nancy M. Cappello, Ph.D. on Twitter: [www.twitter.com/DrNancyCappello](https://twitter.com/DrNancyCappello)

Key Points

- Mammograms are limited in finding cancers in dense breasts.
- In the U.S., breast cancer is the second leading cause of cancer deaths in women.

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Further Information

Are You Dense – Patient Stories: <http://www.areyoudense.org/stories/>

Exposing the best-kept secret: http://www.areyoudense.org/files/1814/5236/2405/JAN_11_2016.two_page_brochure.pdf

Wolfe Mammographic Parenchymal Patterns and Breast Cancer Risk (American Journal of Radiology) <http://www.ajronline.org/doi/abs/10.2214/AJR.06.0635>

Breast Cancer Screening for Women at Average Risk - 2015 Guideline Update From the American Cancer Society (Journal of the American Medical Association)
<http://jama.jamanetwork.com/article.aspx?articleid=2463262>

Insights from the Breast Cancer Screening Trials: How Screening Affects the Natural History of Breast Cancer and Implications for Evaluating Service Screening Programs (The Breast Journal)
https://www.researchgate.net/publication/268527874_Insights_from_the_Breast_Cancer_Screening_Trials_How_Screening_Affects_the_Natural_History_of_Breast_Cancer_and_Implications_for_Evaluating_Service_Screening_Programs

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