



UM RELATO TRANSATLÂNTICO SOBRE A EMERGÊNCIA DO DIAGNÓSTICO PRECOCE DE CANCRO DE MAMA EM MULHERES JOVENS

Texto Joana Preto | Lorna Larsen

Conheci a Lorna Larsen, enfermeira, numa conferência internacional sobre o cancro da mama em mulheres jovens. Durante a sua apresentação para uma plateia de profissionais de saúde e doentes, foi claro o impacto da história sobre a sua filha Shanna. Naquele momento, percebi que a Onco Glam tinha o dever de immortalizar o seu testemunho.

Somos um meio de comunicação que vai além de informar; procuramos sensibilizar, inspirar e criar consciência sobre tudo o que o cancro representa. O nosso propósito não é apenas dar voz ao que o cancro traz, senão também refletir sobre o que leva. Acreditamos, acima de tudo, que da tragédia podem nascer projetos concretos e transformadores – uma convicção que esteve na base da criação desta revista.

O projeto fundado por Lorna, enfermeira e mãe, nasceu da dor de uma tragédia pessoal e hoje simboliza a esperança para mulheres jovens. Apesar da distância de 6914 km (segundo o Google Maps), recebemos a sua história poderosa e comovente. Uma narrativa que, se for lida sob a ótica certa, torna impossível ficar indiferente à necessidade de uma vigilância precoce e consciente para o cancro da mama.

Nota editorial OncoGlam:

Este é um tema de extrema importância que não poderíamos deixar de partilhar, mesmo estando o texto em inglês. A questão do cancro da mama em mulheres jovens é urgente e merece ser discutida a nível global. Para garantir que todos possam aceder ao conteúdo, fizemos questão de adicionar algumas notas explicativas, de forma que a barreira linguística não seja um obstáculo à compreensão e reflexão sobre este assunto. Acreditamos que a partilha de informações é fundamental para gerar consciência e mudança.

FROM TRAGEDY TO HOPE DE TRAGÉDIA A ESPERANÇA

My life changed in an instant, the instant the world changed, the instant my daughter Shanna (Shan) was diagnosed with cancer. Shan was beautiful, inside and out, had a kind heart and a gentle spirit. Shan loved life, time with family and friends, beautiful summer days, art, music, and sports. She was an artist, swimming instructor, and figure skating coach who loved to work with children. Shan was only 23 when she was diagnosed late with metastatic breast cancer. Her symptoms were repeatedly misdiagnosed. Shan's health care providers assumed the most common and didn't rule out the most devastating. Living her beliefs, Shan faced the tests and cancer treatment with determined optimism. Sadly, the predictions of hope, of time, were not to be realized. Shan passed away a few months later. She was only 24.

Shan, like many young women with breast cancer, was diagnosed with advanced disease. At diagnosis, the cancer had spread from her breast, to her bones, and to her liver. Shan had just graduated from university with a visual arts degree, was planning to visit Europe with a friend, and attend teachers college in the fall when she started to experience breast changes. Shan initially presented with breast pain and swelling, and was treated for a common condition. Her symptoms increased and over time included unresolved pain, fatigue, headaches, nausea, and a breast lump. Shan was also treated for a



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fracture following a minor fall while snowboarding. Despite her classic symptoms of cancer in young adults and repeated visits, cancer was not on her health care provider's check list.

Shan was repeatedly reassured that she would be fine, and after raising my concerns, I was also reassured that Shan would be fine. Shan knew something was wrong, I knew something was wrong. As Shan's symptoms persisted, I asked for more testing. It was on her seventh medical visit that Shan was taken more seriously. An abnormal liver function test lead to further testing and an accurate diagnosis of cancer was made. Valuable time against an aggressive, insidious, and often fatal disease was lost. Treatment was too little, too late. Our beautiful girl was gone.

A vida da mãe de Shan mudou num instante, quando a sua filha foi diagnosticada com cancro. Shan era uma jovem bonita, com um coração bondoso e um espírito gentil, apaixonada pela vida, arte, música e desporto. Aos 23 anos, foi diagnosticada tardiamente com cancro da mama metastático, sendo que os seus sintomas foram erradamente diagnosticados várias vezes. Apesar de ter procurado ajuda médica repetidamente, o diagnóstico correto só foi feito após vários exames, quando o cancro já tinha espalhado para os ossos e fígado. A mãe de Shan viu sua filha enfrentar os tratamentos com otimismo, mas o tempo perdido foi fatal e Shan faleceu aos 24 anos. A dor da perda foi imensa, e a mãe ficou com a sensação de que a doença tinha sido negligenciada até ser tarde demais.



THE PAIN OF LOSS

The pain of my loss was unimaginable. My heart was broken. I cried a sea of tears, but it was never enough. I was pushed to the depths of hell. Attempts to crawl out were quickly met with a return to the bottom. Initially, I described my grief as a rogue ocean wave. I felt I was drifting, drowning out at sea. When I tried to reach shore, my attempts were countered by the wave washing away the sand from under my feet, pulling me under and returning me to the sea again and again.

I wanted it to be me, not Shan, not my first born, not my little girl, but life is not always kind. Shan was taken and I was left with the decision to survive or not. I realized through my life experience, that I was gaining an understanding of mental illness, alcohol and drug abuse. You

contemplate whatever will help reduce the pain, but I could not embrace negative solutions. I had taught my children to love life. I knew Shan would want me to experience joy again. I had to try!

Lorna descreve a dor da perda como algo inimaginável, um sofrimento profundo que a levou aos limites do inferno. Chorou incontáveis lágrimas, mas sentia que nada era suficiente para aliviar a sua dor. Inicialmente, comparou o luto a uma onda traiçoeira, sentindo-se à deriva no mar, sendo constantemente puxada de volta ao fundo. Queria que fosse ela a ser levada, não a sua filha, mas a vida não foi gentil. Enfrentou a difícil escolha de sobreviver ou sucumbir à dor, mas, através da experiência, compreendeu as dificuldades da doença mental e do abuso de substâncias. Apesar da dor, sabia que Shan de-

sejaria que ela encontrasse alegria novamente e, por isso, decidiu tentar seguir em frente.

FINDING STRENGTH THROUGH ACTION

I knew I needed professional help and inner strength to get through my grief. I did not believe I could ever get over it, but hoped I could get through it. I would have to work hard, follow my heart and seek professional support. I went down three roads...one, my own grief process, two, preserving Shan's memory, and three, making a difference for young women following in Shan's footsteps.

During my grief, I felt like I was running a marathon. I was frequently exhausted, falling to my knees and unable to run further. I needed support from the sidelines to provide the encouragement, nourishment and the strength to carry on.

The support from counselors, family members, close friends, and Shan's friends helped me to keep getting up, to keep running, and running, and running. But for the longest time I could not see the finish line.

I learned to trust my inner self to guide me through the steps of my grief. Relying on this intuition helped me to know what to do next on both my spiritual journey and my personal grief. I worked to preserve Shan's memory and also navigate my grief. A love of nature resurfaced, supported my healing, and helped me secure hope for the future. All the steps were important to my wellbeing. I was also encouraged by a colleague to use my nursing expertise and health promotion experience to travel the third road. As a registered nurse, I had a career in public health as a health promotion specialist when Shan got sick. I had advocated strongly for young women's health issues, but the importance of breast cancer awareness for young women had never come across my desk.

Finding purpose, making a difference for young women with breast cancer gave me a reason to get up in the morning. I realized that a tangible use of my nursing skills and talents to improve outcomes for young women diagnosed with breast cancer might someday help me find joy. At some point along the way moments of joy did return. My circle of contacts started to widen. I was able to enjoy music again, reading, a glass of wine, dinner with friends, and my grandsons. This process took me through a spiritual reflection, an important assessment of my grief, and hope for the future.

Lorna reconheceu que precisaria de ajuda profissional e de força interior para lidar com o luto, e, embora não acreditasse que pudesse superar a dor, esperava conseguir ultrapassá-la. Decidiu seguir três caminhos: o seu próprio processo de luto, preservar a memória de Shan e fazer a diferença para outras jovens, tal como a sua filha. Sentiu-se como se estivesse a correr uma maratona, frequentemente exausta, mas o apoio

de conselheiros, amigos e familiares ajudou-a a continuar. Confiou na sua intuição para orientar o seu percurso, recuperando o amor pela natureza e conseguindo encontrar esperança no futuro. Ao usar a sua experiência como enfermeira, encontrou um propósito em promover a conscientização sobre o câncer de mama em jovens, o que lhe deu razões para continuar a viver e, eventualmente, trouxe-lhe momentos de alegria novamente.

TEAM SHAN AND THE FIGHT FOR AWARENESS

Team Shan Breast Cancer Awareness for Young Women (Team Shan) was established in Shan's memory to raise awareness and educate young women (15-39 years) about their breast cancer risk and breast health information. At the time, and still today, research on cancer care in children and older adults had made significant gains, but mortality data for adolescents and young adults had not changed. They were the forgotten generation.

Team Shan set out to change the statistics, to improve outcomes for young women diagnosed with breast cancer. Using public health best practice, Team Shan developed, implemented, and evaluated multi-faceted breast cancer awareness campaigns targeting young women on multiple college and university campuses across Canada. The researcher for the campaigns concluded that "Young women, a population at risk of developing breast cancer, need information about breast cancer and their susceptibility to the disease. Knowledge of breast cancer symptoms and self-care strategies provide young women with the opportunity for self-detection and earlier medical diagnosis. Team Shan was successful in developing an effective health promotion strategy to reach thousands of young women on multiple post-secondary school campuses in Canada."

Team Shan continues to reach young women in Canada through billboards, public transit ads,

media ads, presentations, displays, print materials, and online messaging today. The health promotion awareness activities continue to target young women in communities, high schools, and on college and university campuses in Canada. Team Shan also reaches young women virtually around the world through our website and social media platforms. A variety of post reminders, photos, and videos have kept young women engaged and informed. Our messaging encourages young women to take care of themselves.

Through Team Shan, young women have increased their awareness of breast cancer in young women and their knowledge of breast cancer facts, risk factors, symptoms, and self-care. They have understood their breast cancer risk and gained knowledge that will last their lifetime. Women worldwide will face breast cancer in their lifetime. Shan's face and her story has resonated with young women and helped communicate Team Shan messages. Young women have reported on their improved self-care and shared vital breast health information with family and friends. This special message was sent from one young woman impacted by Shan: "Your presentation was very informing and touching; even made me cry a little when you showed the slideshow of Shan's life. She was too young, and had way too much to live for to have everything taken away. Even though I did not know her, from the pictures and your presentation she was a beautiful, adventurous young woman who loved life. I only wish she was here today to tell her story. It's so nice to see she will live on through your presentations and information. I will be sure to pass this information onto my family and girlfriends. Thank you for enabling people to save their own life, and the lives of others! ▣"

There is still no routine breast cancer screening available for young women so they need to self-detect their breast cancer. They need to know their breasts, know the symptoms, check their



breasts regularly, and watch for breast changes outside their normal. Young women also need to overcome help-seeking barriers to be empowered to seek medical advice for unexplained and persistent changes. Empowered to ask the question “*Could this be cancer?*”

Young women have appreciated not being forgotten in breast cancer messaging and have thanked Team Shan for our efforts. Team Shan is proud to have realized our goals for earlier detection and improved outcomes for young women diagnosed with the disease. One young woman diagnosed early reached out to Team Shan with her story: “*I had stage one breast cancer... there is one organization I thank for my life. My early detection was due to Team Shan. I would not have been checking my breasts had it not been for the loss of Shan and her story. I thank Team Shan for running programs in Shan’s memory, for reminding me that breast cancer is not just a disease of older women. Thank you! Thank you! Thank you!*”

Team Shan has used two tag lines over the years. One, Breast Cancer...not just a disease of older women and Young Women...get breast cancer too! Shan loved sunflowers and her last piece of artwork was the bouquet of sunflowers I gave to her when she was not feeling well.

One of the sunflowers has been vectorized for the Team Shan logo and used on our marketing and resource files. In Shan’s memory, sunflower photos have been sent to me from around the world. An animated Shan (Shanimation) has also been developed to help Team Shan engage young women, and share our risk reduction and early detection messaging.

A Team Shan foi fundada em memória de Shan-na para sensibilizar e educar jovens mulheres (15-39 anos) sobre o risco de cancro de mama e saúde mamária. Na altura, a investigação sobre o cancro em crianças e adultos mais velhos estava a avançar, mas os dados de mortalidade entre adolescentes e jovens adultos permaneciam inalterados. A Team Shan procurou mudar essa realidade, criando campanhas de consciencialização sobre o cancro de mama em várias universidades e faculdades no Canadá. Estas campanhas mostraram que as jovens precisavam de informações sobre os sintomas e estratégias de autoexame, possibilitando a deteção precoce e um diagnóstico médico mais rápido. Este grupo continua a alcançar jovens em todo o Canadá e em todo o mundo através de anúncios, redes sociais e outros meios. Graças a essas campanhas, as mulheres jovens aumentaram a consciência

sobre os riscos do cancro de mama e aprenderam a importância do autoexame. O trabalho deste grupo teve um impacto significativo, ajudando mulheres a melhorar os seus cuidados e a partilhar informações vitais com as suas famílias e amigas. O legado de Shan continua vivo, inspirando jovens mulheres a cuidar da sua saúde e a procurar ajuda médica quando necessário.

THE ONGOING MISSION

Through Team Shan I have also educated health care professionals through a variety of strategies including resource sharing, journal publications, and professional presentations. I was proud to present at the first Conference on Young Women’s Breast Cancer and Health hosted in Lisbon in the fall of 2024. I have also advocated strongly through national adolescent and young adult cancer initiatives in Canada and ongoing breast cancer in young women opportunities in Canada and beyond. I am honoured to be a Global Ambassador for the international Breast Cancer in Young Women Foundation. I have connected with other young adult cancer advocates and educational professionals who want to make a difference for young people. I have also had the opportunity to meet some amazing researchers, share their passion, and support their efforts to change the landscape for young adults diagnosed with cancer including breast cancer in young women.

I have found joy in meeting young women across Canada...beautiful, intelligent, young women that give me hope for the future. I have found joy in sharing empathy and an understanding of loss with other mothers who have lost a child too soon to cancer. All of us in a club we never wanted to join. I have found joy in the beauty of wildlife and the natural wonders of the world. As I reflect on my progress, I am proud of both Team Shan successes and my resilience to survive, to live again, to cross the finish line!

Este programa tem educado profissionais de saúde sobre o cancro de mama em jovens mulheres,

utilizando várias estratégias como partilha de recursos, publicações em revistas e apresentações. Lorna teve a honra de estar presente na primeira Conferência sobre Cancro de Mama em Jovens Mulheres, em Lisboa, em 2024, e tem defendido fortemente iniciativas nacionais no Canadá para o cancro em adolescentes e jovens adultos. Foi nomeada Embaixadora Global da Fundação Internacional para o Cancro de Mama em Jovens Mulheres e tem conectado com outros defensores e profissionais da área. Encontrou alegria ao conhecer jovens mulheres e mães que, tal como ela, enfrentam a perda de um filho devido ao cancro. Ao refletir sobre a sua jornada, sente-se orgulhosa dos sucessos da Team Shan e da sua resiliência em continuar a viver e a lutar.

A LEGACY OF HOPE

Since Shan's passing, I have seen improvement in many of the young adult cancer journey steps...treatment, survivorship support, monitoring, and more recently palliative care. My

work advocating for improved palliative care for young adults has also been very special to me. More work still needs to be done on prevention and early detection. Incidence of breast cancer in young women continues to rise and disparities exist globally. Prevention research is a critical component to future improvement in young adult cancer outcomes. Understanding the random and sporadic nature of the disease in young adults and increasing early detection are ongoing challenges. Challenges I continue to pursue with passion and hope worldwide.

Shan loved to teach and now it is her spirit that continues to teach young people to "love what they are doing, to have fun and to stay positive." Her teaching goal was "to provide young people with the knowledge to reach their potential and achieve their dreams." Shan's dreams were lost, but they were the lifeline I tightly hung on to through my journey.

Shan had a smile that would radiate across the room, a great sense of humor, and an infec-

tious laugh. I still, and always will, miss Shan every minute of every day. Her memory lives on through Team Shan and my efforts to make a positive difference for young women everywhere, my renewed purpose and joy!

Após a morte de Shan, Lorna tem observado melhorias no tratamento, apoio à sobrevivência e cuidados paliativos para jovens adultos com cancro, áreas pelas quais se tem empenhado. Contudo, ainda há trabalho a fazer na prevenção e deteção precoce, pois a incidência de cancro da mama em jovens mulheres continua a aumentar. Lorna acredita que a investigação em prevenção é fundamental para melhorar os resultados do cancro em jovens adultos e continua a lutar por isso. O espírito de Shan, que amava ensinar, permanece vivo, inspirando jovens a "amar o que fazem, a divertir-se e a manter-se positivos". A sua memória vive através da Team Shan e do esforço da sua mãe em fazer a diferença entre as mulheres jovens, proporcionando-lhe uma nova razão para viver e encontrar alegria. ☺



Shanna Larsen 1981-2005

Young Women... get breast cancer too!



teamshan.ca

