



MEET LOUISE



The first diagnosis came in June 2010. Louise of Canterbury, United Kingdom, visited her general practitioner (GP) about the discomfort she was experiencing in her breasts. Her GP referred her onto a two-week fast track for a breast screening. During that appointment at her local hospital, Louise underwent a biopsy, a mammogram, an ultrasound, and several other tests, all within just a few hours. She received those test results that same day; it was breast cancer.

Louise was shocked by the news, as breast cancer had not even entered her thoughts. At age 42, she assumed the cause of her enlarged breasts and the discomfort she felt was simply due to a hormonal change, thinking her symptoms were related to perimenopause.

Louise was referred to an oncologist and a surgeon at her local hospital. Because of the size of the lump in her breast, she underwent five months of chemotherapy, then surgery in December 2010, followed by radiotherapy at the beginning of 2011. Louise continued seeing her oncologists for the next four years.

Then in March 2015, Louise received another diagnosis. The breast cancer had spread to her liver, lungs, bones, and brain. She had metastatic breast cancer.

At the time of this profile, Louise was waiting to change treatments as the last round of chemotherapy was

unsuccessful. She presently sees her oncologists every three-to-four weeks.

Apart from the daily fatigue caused by her treatment, Louise manages to carry on with everything that she needs to do in her daily life, like caring for her children. A mother of four, aged 24, 22, 16, and 14, her two teenagers live at home with her, while her eldest child lives with his dad and her 22-year-old is at university. Given her responsibilities, she focuses on not doing too much, so she doesn't wear herself out. For Louise, living with this disease means spreading out her energy and using the energy she has to do the things she needs to do, not necessarily the things she wants to do.

Since her diagnosis in 2010, the support Louise has received from her friends and family has been magnificent. While most of her family lives far away, they are as supportive as they can be given the distance between them. When she does stay with her family, she is well cared for and is treated like a princess. Her ex-husband is also very supportive, along with a group of close friends who often 'scoop' her up and keep her going. Louise admits that a lot of the time, she couldn't do what she does if it were not for her friends.

One of the challenges of living with metastatic breast cancer is that due to her independent nature, Louise finds it difficult to ask for help. She'll try and accomplish



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a task on her own, but then find she's completely worn herself out. When her friends inquire why she doesn't ask for help, she tells them she thought she could do it herself.

Thanks to the local hospice, Louise has received counseling and learned to say "no" to the things that do not suit her, such as having to turn down invitations to go for lunch or coffee because she doesn't have the energy for it. Counseling has enabled her to say "no, thank you" rather than struggle to make it through a social engagement.

In addition to counseling, Louise receives monthly phone calls from one of the community nurses on staff at the hospice who checks up on Louise. The hospice has provided great backup support to Louise, especially when she couldn't get practical help from her hospital team. It was the hospice staff that really listened to her, which was most helpful. Louise believes the situation can be much harder if you don't feel listened to, if you don't have someone taking notice of the symptoms that you're reporting.

Louise recognizes that many people hear the word hospice and worry because it's mostly known for end of life care. But, she's learned firsthand that hospice is not a scary place where they help you to die. Rather, it is there to make things easier for people living with an illness and helpful for practical solutions.

Louise joined a Facebook support group for people with metastatic breast cancer and has found it useful

to read about other people's experiences and to ask questions about treatment from others who have already gone through it. She's found that more meaningful and helpful than reading information from a fact sheet. Louise encourages people to refrain from looking at statistics online as that will surely frighten them, or the information may be out of date by the time they read it.

Louise is very much of the mindset that knowledge is power and believes that if you know what you are dealing with, you can find strength, and you don't have to fear the unexpected. When you are aware of symptoms and how breast cancer can spread, you can alert your medical team, and they can respond and take action earlier rather than later.

Louise's outlook on this disease is pragmatic; she shows up to receive treatment and takes the necessary medication. She emphasizes that there's no prize for putting up with the side effects of cancer treatment so take the medication that is intended to help you deal with those side effects and then get on with living your life.

Louise decided to take part in healthcare market research studies to share her experience of what it has been like living with breast cancer in the hopes that it will help others who have been newly diagnosed with the same disease. Louise acknowledges how scary it can be when you are first diagnosed with such a disease and the importance of realizing that there is support out there because sometimes you need somebody to point you in the right direction. Louise has been fortunate that in



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the Facebook support group she belongs to, there are a couple of women who live locally, and she has been able to meet them for coffee to learn from and share in their experiences. She cannot overstate the importance of meeting others who are in the same situation and how helpful it has been for her.

Louise has learned and wants others to know that you must keep on living, and don't give up. Remember you're **living with** cancer, not **dying from** it. There are women in her online support group who have lived with metastatic breast cancer for 10 years because they received the right treatment that has kept their cancer stable. She realizes that this message does not apply to every person, as some people are diagnosed very late, and the disease has unfortunately progressed.

The advice Louise would offer to someone newly diagnosed with breast cancer is to try not to let panic set in. A breast cancer diagnosis is by no means the end of the world. Nobody gets to say when your expiry date will be. She's been living with metastatic breast cancer for over four years, and while the disease is not curable, it is treatable and can be managed like any chronic condition.

Louise hopes that new, kinder treatments other than chemotherapy will be developed in the future. Yet, she says that some of the side effects are a small price to pay for being alive.