



MEET NICOLE



Nicole is a 37-year-old leukaemia survivor who lives outside of Philadelphia, Pennsylvania, in the United States.

Nicole was diagnosed just after turning eight-years-old when she was in third grade. Otherwise a healthy child, she had been suffering from joint pain and swelling and was initially misdiagnosed with septic arthritis and was receiving treatment for that condition. When it persisted, her parents took her to Children's Hospital of Philadelphia (CHOP) where she was finally accurately diagnosed with acute lymphocytic leukaemia (ALL). ALL is the most common form of childhood leukaemia, and fortunately for Nicole the doctors at CHOP were able to make an assessment and layout a treatment plan.

Nicole's treatment in the initial stages was oral chemotherapy and bi-weekly shots. She was on drugs such as vincristine and methotrexate, as well as oral prednisone. She also had to go regularly for spinal taps and bone marrow tests. Additionally, she took part in a study which introduced Adriamycin, from which she suffered some adverse effects, but was ultimately successful.

It was understandably a scary experience for an eight-year-old. However, Nicole feels that the people at CHOP are top notch and remembers that they were always supportive and made the most of the children's

time at the centre. She remembers having to stay at the hospital and the doctors were having water gun fights with the syringes and how their fun attitude made it more comfortable for her to be there.

While it was certainly scary for Nicole and her family, once they knew the illness could be treated, they were able to just focus on getting through it. While there was always a little bit of fear, they felt more secure once they knew they were in good hands and knew what was going on. She was surrounded by other kids and their families going through similar situations, so Nicole always felt like she had a supportive group of people around her.

Nicole and her family have always wondered if heredity played a factor in her leukaemia. Her paternal great grandfather presumably had leukaemia when he was older. Additionally, her father has an immunoglobulin disorder that is indicative of a higher risk of leukaemia. However, no other direct relatives have been affected.

Growing up fighting leukaemia has affected Nicole in both positive and negative ways. It helped shape a formative part of her life during the 2-3 years that she underwent treatment. She was 11 years old at the end of her treatment. On the positive side, it led to her being more open and accepting with people. She learned that she had a determination that she could overcome any



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barriers. On the flip side, as she grew older, it created a big question mark when she thought about her family's history in relation to starting her own family. She has a six-year-old daughter and has worried about the possibility of leukaemia being passed down to her and how she'd handle that if it happened.

Cancer has been a part of Nicole's life since she was so young that in many ways, she feels like it has never left her, because many people she knows have been affected by it. So, she feels like it never really goes away. Even one of her closest, lifelong friends has dealt with breast cancer, just recently celebrating her five-year cancer-free mark. So, in a positive sense, because she's been through what she has, Nicole is able to be there to support others like that friend because she can understand where they are coming from and be a good part of their support system.

While Nicole was going through treatment at CHOP, she found support through not only other children and families there but also through a child psychologist on staff who met with her and also offered the service to her younger sister. Nicole appreciates this because there's normally so much emphasis on the patient, but CHOP was also ensuring that her siblings and parents were taken care of in the same way that the patient needed to be cared for. They helped her parents develop tools to help them all manage the stress of the situation.

The reason Nicole joined M3's panel is because she had reached a point where she wanted to be sure data was collected because she believes that the more people

share their stories and experiences, the more we know what healthcare is like and how healthcare is helping and where there are challenges with healthcare. She believes it can help others if the data is collected, so that we can see best practices or highlight areas where healthcare is struggling or is going really well.

There's a young boy in Nicole's daughter's pre-k class who has ALL and she has talked with his mother. It still frustrates her that the treatment period for this young boy is on such a similar path as her treatment was, expecting it to run over two to three years, which for a child is a long time. Nicole wishes there were more options. While it's wonderful that this treatment is successful, with the length of time being a big factor for the child and the family, it's a real struggle. Especially when factoring in decisions like whether or not the mother should leave her job to stay home and care for her child and risk losing the healthcare that is curing him because she's getting it through her job. If there were treatment options that were more condensed, even if they were more intense, like what her friend with breast cancer went through, then at least families would have a choice.

The advice that Nicole would give, to either an adult who has just been diagnosed or a parent with a child just diagnosed, is to rely on the people closest to you. There will be tough moments and it will be challenging to get through any treatment. If you try to handle it all yourself, as many of us are accustomed to doing, it's going to become insurmountable. She has found that if you just look and reach out, there are so many people around you who are willing to help. Nicole believes that



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support is everything and you need to find your good listeners. And, if you don't have those people in your life, then you should get a therapist. Going through cancer treatment is a major life adjustment, even after you move forward after treatment. It will affect things you haven't even considered. Having someone to talk to, whether it's a professional or a support group or family and friends, is essential. Beyond that, she advises that those living with a condition take it one day at a time. Everything is turned upside down when cancer hits, and you don't know which way things will go. So, even if it sounds cliché, taking one day at a time and appreciating the small things is important. She also believes it's important to recognize that you will overcome your challenges with your doctor's advice, so you shouldn't get too caught up in the anxiety of the moment and instead just push through it.

Nicole hopes that all of those who have been affected by leukaemia can continue to find the joy in life and not sink into the fear. It's always lingering but there's also a greater appreciation for family and friends. She believes that what's important is doing the things you love and focusing on that and not letting fear take over.