



Profile:

Christina Mangurian, MD, MAS

By Trudie Mitschang

AS CAREGIVER for her son who was diagnosed with Wiskott-Aldrich syndrome as an infant, Dr. Christina Mangurian also wears several other hats. She's a psychiatrist who delivers mental health services to patients and their families, a scientist who understands the healthcare system and a passionate advocate for improving care for all patients. Her experience with her son's bone marrow transplant in particular taught her impactful lessons about the needs parents have for compassion and emotional support when navigating the care and treatment of a sick child.



After enduring months in the hospital with her infant son during his bone marrow transplant to treat Wiskott-Aldrich syndrome, Dr. Christina Mangurian wants to help other parents navigate similar experiences.

Trudie: How old was your son, Anderson, when he was diagnosed with Wiskott-Aldrich syndrome?

Dr. Mangurian: Anderson was diagnosed with the most severe form of Wiskott-Aldrich syndrome, a genetically inherited immunodeficiency disease affecting one in 250,000 males, when he was just 4 months old. Children with severe Wiskott-Aldrich syndrome die early of infection or hemorrhage if not treated with a bone marrow transplant.

Trudie: Tell us about Anderson's bone marrow transplant.

Dr. Mangurian: Anderson had a bone marrow transplant in August 2012 when he was 10 months old.

Children receiving a transplant from an unrelated donor or via cord blood donation can be hospitalized for up to three months — all in an isolation room because of the risk of infection. My family had already endured a three-week hospitalization when my son was only 1 month old, so I knew it would be stressful on all of us. I had to develop a plan to take care of not only Anderson, but also my 4-year-old daughter, my husband and myself both physically and emotionally during this marathon. That's why I'm passionate about helping other families do the same.

Trudie: What did this experience teach you about the healthcare system?

Dr. Mangurian: Despite all of our

planning, the love showered on us by family and friends, and support from the transplant providers, nothing could prepare us for the reality of the hospitalization. Until I began “living” on the transplant unit, I hadn't really understood what it was like to be on the other side of the patient-provider relationship. It opened my eyes to the universe of fear and vulnerability, where healthcare providers are in complete control and patients (even those who are doctors) are at their mercy across a wide logistical and emotional divide.

Trudie: What was it like being on the other side of the patient-doctor equation?

Dr. Mangurian: Feeling absolutely no control over this life-and-death situation, my husband and I struggled constantly with emotions such as vulnerability, fear and anger. As a psychiatrist, I knew these feelings were normal, but there was no mental health professional on the transplant team assigned to help us. Social workers were available, but they seemed to deal with the “problem cases,” not the easier ones such as ours. Child life specialists made my son's daytime life as normal as possible, but they did not attend to my emotions. Thankfully, I had my own psychiatrist and my husband, parents and friends to turn to for the emotional support I needed. Many families are not so fortunate.

Trudie: Why do you think the treatment process for chronically ill children is so hard on families?

Dr. Mangurian: It struck me again



and again that, because of the increasing complexity of medical care, doctors do not seem to have the time to take the “emotional temperature” of patients or their caregivers during prolonged hospitalizations, nor are providers thinking critically about essential, patient-centered concerns to facilitate wellness. In my opinion, we were treated at the best pediatric bone marrow transplant unit in the country, but the empathic failures made me wonder about the emotional experience for families at other hospitals.

Trudie: What recommendations do you have for doctors in these situations?

Dr. Mangurian: I believe doctors who are treating children for prolonged periods should ask the parents how they are feeling about being in the hospital every day. If this is unreasonable given time constraints, then add a team member to fill this role. Again, there is plenty of evidence that children do better if their parents are emotionally grounded. By not being asked, parents may have the impression the doctors don't care, and clinicians may miss important warning signs of parental depression or anxiety that could negatively affect outcomes for critically ill children.

Trudie: What was the turning point for your family?

Dr. Mangurian: About a week after the transplant, the chief of the pediatric bone marrow transplant unit visited us on the day he returned from vacation. Without ceremony, his first words to me were: “Hi, Mom, how are you doing? Do you need a hug?” As a psychiatrist, I was taught not to hug my patients, but at that moment, I did need a hug, and I needed it from him. I needed it from my son's doctor, the person we were counting on to save his

life, the person who was supposed to help us through this terrible ordeal. Although his bedside manner is not generally “touchy-feely,” our doctor knew I needed him to cross the doctor-patient-parent boundary. His small gesture took no extra resources and little extra time. Yet, it instantly made me feel better. And, that is what ultimately makes him not just a good but a great doctor.

son was hospitalized for his bone marrow transplant.

Trudie: Put on your psychiatrist hat. How can parents/caregivers manage stress and anxiety when dealing with a family member's illness?

Dr. Mangurian: This is very individual. I encourage parents to talk to friends, family, colleagues, spiritual leaders and counselors — whatever fits them. And, there is no shame in seeing

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Trudie: What advice do you have for parents/caregivers?

Dr. Mangurian: I think most caregivers are the experts when it comes to caring for their children. But, what most caregivers don't prioritize is their need for sleep, a healthy diet, exercise and socializing. Doing these things helps them maintain their own well-being, which is directly related to how well the child does.

Trudie: How well did you follow your own advice?

Dr. Mangurian: Initially, during my son's first hospitalization, I did not follow this advice at all. I got no sleep and no exercise for three weeks. This led to my first experience with postpartum depression. I recovered through the support of family, friends, psychotherapy and medication. I learned the hard way, and it forced me to develop a plan to manage my own well-being while my

a psychiatrist to get medications if they need them.

Trudie: What has this experience taught you about yourself?

Dr. Mangurian: I learned what really matters in life. I learned how fortunate I am to have so many people who love me, especially my husband, parents, extended family and friends. I have also learned I want to give back and help others navigate this experience in ways that are helpful to their families.

Trudie: Looking back, if you could give your younger self advice, what would it be?

Dr. Mangurian: I would tell myself that all of the planning we put in would pay off in the end. I would tell myself that things will be OK. ■

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