

## Childhood Leukemia and Pain: A Family's Perspective

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Jordan is a beautiful child with big brown eyes, long eye lashes, and golden brown hair. She looks like a little girl destined to be homecoming queen. She has an adorable smile even with her two front teeth missing! Her story starts three years ago when she was just three-years-old-- a healthy, happy little girl living a Norman Rockwell-kind of life with her parents and younger brother in rural Ohio.

Jordan loved to be outside running and playing with the family dog. However, bruises started appearing. Her mother thought nothing of them since Jordan was very active. When the bruises kept appearing in places that they shouldn't be her mother took her to the family doctor. The doctor did blood work and found Jordan's blood count was abnormal, so she was referred to a pediatric cancer specialist at the nearest medical center an hour away. The family didn't go to the city very often, so they made it a special day and went for a carriage ride before her appointment; they had so much fun. Looking back, her mother is thankful they had that day. No one had any idea how rough the road ahead would be.

Jordan's blood and bone marrow were tested. The diagnosis: Acute Myelogenous Leukemia (AML). Fifteen to 20 percent of childhood leukemia is diagnosed as AML. "Between 80% -85% of children with AML can achieve remission. This means that the leukemia can't be seen under a microscope, but it is still there. More treatment is needed before it is cured. The cure rate is about 50/50," stated Dr. Michael Rytting, Associate Professor, Department of Pediatrics and Leukemia at MD Anderson Cancer Center in Houston, Texas. Certain subtypes have a higher cure rate.

Chemotherapy treatment for AML is very intense. Jordan was in the hospital for several weeks and then in and out as the treatments lasted for over a year. The first cycles of chemotherapy are called induction chemotherapy. The goal is to quickly kill as many cancer cells as possible. The chemotherapy drugs damage normal cells as well as leukemic cells, so Jordan was susceptible to infections and excessive bleeding. She had to have blood and platelet transfusions.

Jordan was often nauseated and vomited. She was tired; her hair and eyelashes fell out. She seemed to hurt.

Jordan's parents didn't realize that she might feel pain. They were so concerned about the leukemia that they didn't think to ask about pain and how it could be managed.

"Parents can feel overwhelmed when their child is in the hospital," says Dorothy Stratman-Lucey, RN, MSN, BC, PNP, Pain Management Coordinator and PeriAnesthesia PNP at Shriners Hospital for Children in St. Louis. Stratman-Lucey goes on to say, "We can't let parents give away their role ... the parents are part of the team." It's important to report pain for quality of life, but also because unrelieved pain can suppress the immune system and delay healing. Jordan's parents were afraid the pain was a sign the leukemia was worsening.

According to Dr. Steven J. Weisman, Jane B. Pettit Chair in Pain Management, Children's Hospital of Wisconsin, and Professor of Anesthesiology and Pediatrics, Medical College of Wisconsin in Milwaukee, Wisconsin, "Pain can be due to the leukemia itself. Often these children present with generalized achiness and malaise. They can have moderate-to-severe pain from the leukemia expanding in the bone marrow, liver, or the spleen. Sometimes, the leukemia has spread to the central nervous system and patients can have severe headaches. Other times, collections of leukemia cells can press against nerves, which cause severe neuropathic pain. Once treatment begins this disease pain can often go away quite rapidly. AML and the other types of leukemia usually respond well and rapidly to chemotherapy. However, this can quickly be followed by pain from the treatment itself. Various chemotherapy drugs can irritate nerves and cause another type of neuropathic pain. In addition, as the bone marrow is cleared out of leukemia cells and the remaining few normal bone marrow cells are killed off by the

chemotherapy, almost all patients develop severe irritation of the lining of the mouth and even the entire gastrointestinal track. This results in severe pain.”

Jordan did experience irritation in the lining of her mouth. She was given oral rinses, but as a three-year-old, it was hard. The nurse also reassured them that Jordan’s pain was being assessed and treated regularly. Her parents were encouraged to watch for and report any signs of pain. Jordan’s mom said she noticed facial expressions that indicated Jordan was having pain.

The illness, its treatment, and the pain took a toll on Jordan’s family. When one member of a family has cancer, the whole family is affected. In fact, the American Psychological Association considers these family members to be “secondary patients.”

Staci Holweger is a mother whose daughter has been through extensive AML treatments. Her advice for parents is to “find a support group that really benefits you; one that gives you resources, information, and support to help you and your child.” Staci also shares “no mother would want her child to go through this, but there have been many positives for us as a family. Of course, we are more health conscious now, but we are also a more caring, giving, and compassionate family.”

For Jordan, the induction chemotherapy destroyed all of the leukemia cells. Since there was no sign of the leukemia in her bone marrow after the induction chemotherapy, she was given further cycles of chemotherapy to reduce the risk of the leukemia coming back. Jordan will be closely monitored, but her future has hope. It’s been a long road and there is still uncertainty, but for now her parents feel calmness as Jordan and her brother pet the family dog. She’s home and she’s smiling. It’s miraculous what a family can endure with the love and support of family and friends, faith, good medical care, and gratitude for the simple things many take for granted.