

She wanted to see Bermuda one last time before she died

'It was her wish, she just wanted to be at home with her family' says dad of 25-year-old. Confined to a wheelchair since childhood, Shalimar Williams died last weekend

It was Shalimar Williams' last wish to die in Bermuda so she could be near the "blue water and pretty houses."



The 25-year-old knew she would be going against her doctor's advice but she begged her parents to take her home.

Shalimar was diagnosed with Morquio Syndrome - which stunted her growth - when she was just two years old. And when she fell ill in recent months, she was adamant she did not want to spend her last days at Boston Children's Hospital.

So, attached to a breathing machine and knowing she had just days to live, she was flown home in an air-ambulance with mom, also Shalimar, by her side.

Mrs. Williams said: "As we flew I told her what I could see out the window, I described the island to her. I said I could see the blue water, the pretty houses and St. David's Lighthouse.

'I said 'Hang on in there baby, we are home' and as we touched down we both started to cry. I will never forget that journey."

Her father Gary added: "She understood everything, she was very aware of what could have happened.

"We just didn't know if we would lose her on the way. It was a very trying time, but it was her wish, she just wanted to be at home with her family."

Shalimar - who was known as Shal - was taken into intensive care at King Edward VII Memorial Hospital. She was thankful to have survived the flight and seemed to perk up knowing she would be able to say goodbye her friends and family.

But Mr. and Mrs. Williams got a phone call on Sunday, March 15 saying Shalimar had died - just four days after flying home.

Late last year Shalimar complained of headaches and it was discovered she had Hydrocephalus - fluid on the brain.



Mr. and Mrs. Williams feared the worst and enjoyed one last family cruise together in December.

Shalimar was admitted to Boston Children's Hospital in early January for surgery to drain the fluid. Shalimar eagerly asked the doctor whether the surgery would affect her memory, as she didn't want to forget the good times. But unfortunately the day before surgery Shalimar's lungs collapsed one after the other.

Heart problems

Mr. and Mrs. Williams of Ord Road, Paget, knew something was wrong when Shalimar was just eight months old as she couldn't sit up by herself. She eventually took a few steps on her own but tended to walk on her knees using a pull-walker.

Morquio Syndrome prevented Shalimar from growing taller than about 2ft. She also suffered curvature of the spine, heart problems and had a hearing impairment. Shalimar was thought to be the only sufferer of Morquio Syndrome in Bermuda.

Mr. Williams said: "As parents we were full of anxiety when we were given the diagnosis.

"We wanted to search for all the ways we could help her and we wanted to get her all the medical care she needed."

Mrs. Williams added: "We were never given a time limit, but we were determined to let her live her life.

"We wanted to make sure she had a normal life like any other kid and get the education she needed."

Shalimar spent a lot of her life going in and out of hospital. When she was just a toddler she had spinal fusion surgery and had to wear a head and neck halo for about three months.

Shalimar started using a wheelchair when she was about six years old and although she didn't like people staring at her she adapted well.

Hip and arm surgery

Then when she was about eight years old she had to have hip and arm surgery and her parents proudly remember how she was determined to go to school even though she was in a body cast from her chest to her toes. She lay on her back in the middle of the classroom as she was being taught.

Shalimar remained "pretty healthy over the years" but returned to Boston Children's Hospital once or twice a year for check ups.

Mrs. Williams said: "She never complained about her condition, she wouldn't let anything get to her.



"She just learned to be content and enjoyed nothing better than helping others. She was so loving and caring and would often put others before herself."

Shalimar attended Elliot Primary School, Dellwood Middle School and CedarBridge Academy. Her parents described her graduation day as a "very, very happy moment."

Mrs. Williams said: "She loved school, she was very inquisitive and always had questions.

"She was like a sponge, she soaked up all the information, but always wanted to learn more. She had a thirst for knowing things."

Shalimar was a very independent young woman and travelled to New Jersey on her own once a year. She always attended Camp Oakhurst (where she was the first international student) for two weeks, then stayed with a friend for another week.

She was also a volunteer with Meals On Wheels, helping to label and deliver the meals to those in need. Volunteers coordinator Gladys Madeiros described her as an "exemplary worker with a 'can do' attitude."

But it had always been Shalimar's dream to work in the tourism industry.

Mrs. Williams said: "She wanted to be a concierge at a hotel. That's what she was all about, helping others.

"She had the personality that draws you in, she was very outgoing and loving."

Mr. and Mrs. Williams most cherished possessions now include a signed photo of Shalimar with George Bush and her journal that she wrote in most days.

Mr. and Mrs. Williams said they would miss their daughter "just being there." She loved watching TV especially The Young and The Restless, listening to music, playing on the Internet and chatting to her friends on the phone.

Mrs. Williams said Shalimar knew so many people that some people just knew her simply as 'Shalimar's mamma.'

She said: "Our daughter was our life, we are going to miss her so much."



All smiles: Shalimar Williams always "put on a brave face" and refused to let her disability get the better of her. She is pictured aged three wearing a neck and head halo, which she had to wear for three months after surgery.