

The Document Game



» P R O F I L E :

Ashley Shaff

CALIFORNIA

~ 22 Years Old,
35 Hospitalizations,
a Terminal Diagnosis,
and a Complicated
Medical Journey...

*“I couldn’t be left
alone with my
thoughts and pain;
no, instead I was
forced to regurgitate
a horrific medical
journey, once again.”*

– Peggy Frank

Twenty-two-year-old Ashley Shaff has spent her entire life in and out of hospitals. Ashley is missing genetic information on the short arm of chromosome 20. She is the only person in the world known to have this condition. The missing genes caused a hole in Ashley’s heart, a lack of growth hormone, and a narrowing of the arteries in her lungs. As a result, only about half of Ashley’s lungs function and her condition is described as terminal.

Ashley’s mother, Peggy Frank, is Ashley’s advocate and her librarian. Peggy has managed her daughter’s care from the moment she was born. She keeps track of her extensive and complex medical records stored in boxes, binders, and personal memory, dating back to eye surgery at the age of nine months.

Ashley has been the patient of at least 36 doctors and has been hospitalized over 35 times in 12 different hospitals around the nation. Her list of medical procedures includes heart surgery, two adenoid surgeries, four cardiac catheterizations, and three pulmonary angioplasties. Keeping order in this jumble of critical information is a source of frustration and desperation for Peggy—and a danger for Ashley.

As the volume of Ashley’s medical records grow, it becomes more challenging for Ashley and Peggy to play the “document game.” Peggy is left to keep track of every detail in order to retell her daughter’s medical history during even the most stressful times. She must recite it over and over—hundreds of times—because Peggy is the only source of information that follows Ashley around.

In addition to providing an oral history, Peggy transports binders filled with laboratory reports, x-rays, medication lists, and medical reports. Despite Peggy’s best efforts to accumulate all the relevant data, she is always fearful she has forgotten or is missing crucial information. Hospitals and physicians are not accustomed to providing the detailed level of information that Peggy needs.

Peggy knows that even during the most critical times, she is the lifeline—the only source of information that connects Ashley’s complicated medical history with her current care.