



Bath time made easy



Photos courtesy of the Bromley Family

Having a bath is such a simple thing, for most of us. We take it for granted. Don't even think twice. A quick bath at the end of the day ... five minutes and you're out, warm and cozy.

It takes Kathy Bromley over an hour to give her daughter Shannon a bath. Shannon is 16 years old and weighs 77 pounds.

"I can't get her in and out of the tub by myself," says Kathy. "To bathe her, I have to undress her, get her in a lift, lower her into the tub and bathe her. Then I have to do it all in reverse. And in reverse, she's very cold, stiff and cranky."

Kathy is trying to explain what it's like, caring for her daughter who has Angelman Syndrome, a genetic disorder that means she can't walk, talk, feed herself, or even sit up on her own. Shannon has long blond hair tucked in a tidy ponytail, bangs, and a wide grin. Her mother describes her as a gentle, quiet but also very social child who loves activities like swimming, sit-skiing and being read to. Her parents are clearly very capable and entirely devoted to her; they have even produced a brochure about Shannon to help people understand and relate to their daughter. But tending to her complex needs is exhausting.

“Everything to do with Shannon takes time,” Kathy continues. “This is a child who sees 28 different specialists. And she recently had three years of extreme ill health, including major surgery. That’s the really big stuff, but even moving her around her own home takes a lot of time and effort.

We have a little two-bedroom bungalow, and it’s not very accessible, which makes everything we do with Shannon take more time. Yet we’re forced to fit into the same time schedule as everyone else. We’re tired. We’re very active, inclusive parents. We don’t want Shannon sitting around watching TV all day. We’ve decided we’re going to have fun in this life and not just disappear into a black hole and complain. But sometimes, you think - this is just way too much work.”

While there’s little anyone can do about Shannon having to see 28 specialists, the

renovations funded by Giving in Action should make caring for Shannon at home significantly easier. The changes to the entrance, bedroom, and the addition of an ensuite designed just for Shannon will make the entire house more accessible. Kathy will be able “to whisk her in and out of the tub in 15 minutes, so a quick bath could be a quick bath.” Shannon, who loves to be around people, will be in the middle of the action with her new bedroom door right off the family room. “It will no longer be an effort to include her in family activities, as she’ll already be so close by,” says her mom.

Kathy also foresees a multiplier effect in the entire family from the renovations. “Shannon feeds off how people feel around her, so if we’re happier and less tired and frustrated, she does much, much better. As a family, we try to keep some sort of normal perspective. I think this will help us a lot.” 🌸

