

# Fulfilling the dream of family



## **For people with MS, adoption can be the answer.**

by Aviva Patz

When Andy Rafferty was diagnosed with relapsing-remitting multiple sclerosis at age 22, he made a conscious decision not to have children even though he'd always wanted them. He recalls thinking at the time: "It would be selfish to condemn a loved one to a future of caring for me. And how could I raise a child that I could never even play catch with?"

Twelve years later, thanks to a few twists of fate, he is a father to two school-age softball players whose teams he coaches, and he couldn't be happier. "I could not overexaggerate the blessing my daughters are," says Rafferty, an executive sous-chef in Redmond, Washington. "Lily [12] and Autumn [10] are now what keeps me up, keeps me moving. They are like a daily medication that is 10 times stronger than the drugs that come in a syringe."

The road to adoption may look different for every family, but for people with MS, it can mean the fulfillment of a lifelong dream. Here's what you need to know about becoming an adoptive family when one or both parents has MS.

### **Why adopt?**

People have varied motivations for adoption. "Those who adopt due to reasons of infertility or disability generally do so because they want to love and parent a child, and it is either impossible or not advisable that they become pregnant," explains Chuck Johnson, president and CEO of the National Council for Adoption.

It's important to note that for women with MS, several large studies have demonstrated that pregnancy, labor, delivery and the incidence of fetal complications are no different in women

who have MS than in control groups without the disease, according to the National Multiple Sclerosis Society.



**Kat and Justin Snyder decided that adoption was the best option for them to start a family.** Photo courtesy of Kat and Justin Snyder

After getting married at age 24, Kat Snyder and her husband, Justin, spent the next five years trying to get pregnant, even changing her disease modifying therapy (DMT) to one that is thought to be safe during pregnancy.

“I always wanted to be a mother — that was my dream,” says Snyder, who was diagnosed with relapsing-remitting MS in 2005 at age 20. After two rounds of in vitro fertilization (IVF) and an ectopic pregnancy that led to emergency surgery and then a bad MS relapse, the couple gave up on having a biological child. They started looking into adopting without knowing whether it was even a possibility with Snyder’s MS. Ten years later, Snyder and her husband have a 5-year-old daughter, Claire, and a 21-month-old son, Carson, and are so grateful for the chance to have adopted them at birth.

Others might choose adoption for reasons that have nothing to do with their MS but simply out of concern for the welfare of children.

“There are so many children in foster care around our country, we felt called to help in some capacity,” says Melissa Evensen of North Dakota, who wasn’t yet diagnosed when she and her husband, Todd, adopted their daughter. She learned she had relapsing-remitting MS in 2019, after she and Todd finalized the adoption of Jocelyn, now 10, a special-needs child the Evensens had been fostering for six months. The Evensens also have two biological children,

Abigail, 17, and Natalie, 15. And even now, with the fatigue, difficulty balancing and short-term memory lapses that come with her disease, Melissa is still considering renewing the family's foster care license so she and her husband can continue to care for children with special needs.

### **The challenges**

The adoption process for people with MS or any illness or disability is no different than for people without them. According to [Childwelfare.gov](http://Childwelfare.gov), most people are eligible to adopt regardless of their age, income, or sexual orientation, or whether they are married or single, and having a disability is not grounds for disqualification. "Most adoption agencies will consider a prospective adoptive parent with disabilities as long as they can demonstrate that the disability will not prevent them from parenting the child," Johnson says. That's one reason all prospective adoptive parents are required to provide a medical evaluation, whether they have a disability or not. Many adoptions also require references from family and friends.

People with MS do face one unique hurdle when it comes to open adoptions. "Most infant domestic adoptions involve openness with the birth parents, and the birth parents may not be open to selecting a family in which someone has a disability," Johnson says. "However," he adds, "I have personally worked cases where the birth parent selected families with known disabilities or past illnesses that were required to be disclosed, including polio, amputations, cancer and more, so it's not impossible." International adoptions may be trickier, he adds, as many countries have additional health requirements that people with MS might not meet.

### **The process of adopting**

When it comes to adoption, there are many different types and options. According to [Childwelfare.gov](http://Childwelfare.gov), you can adopt children from the foster care system, from other states or jurisdictions or from other countries. You can adopt infants domestically through a licensed private agency or via an attorney (independent adoption); and you can even adopt an adult — to formalize an existing relationship, for example, secure inheritance rights, or provide continued care for someone with disabilities or cognitive delays. Adoption training and requirements can vary from state to state and even from one county to the next.



**Melissa Evensen's family consists of both biological and adopted children.** Photo courtesy of Melissa Evensen

Evensen adopted from the North Dakota foster care system through a program called Adults Adopting Special Kids (AASK), which finds homes for children who have a mental or physical disability, are older than typical adoptive age, or are part of a sibling group. "Our daughter was our 18th foster match in almost a year and a half," Evensen says. "When she came to us, her biological parents' rights had already been terminated; once other biological family adoptive options were ruled out, we were given the first opportunity to be an adoptive match since we had already established attachment and permanency." Evensen and her husband were thrilled to have the opportunity to adopt the child they had been fostering.

For Rafferty, a private adoption through an attorney made the most sense since he was adopting his then-girlfriend's daughter. "It was expensive, time-consuming and also quite the mound of paperwork," he recalls. "I hired a lawyer to make sure it was done correctly but I was doing most of the work and she was checking it," he remembers. One step he found a bit funny was the inspection of his household, including going through a checklist of childproofing, fire extinguishers, background checks and more.

"All of this happened even though she had already lived with me almost her entire life!" he says. He ended up having his second daughter, Autumn, biologically with his girlfriend, and after that relationship ended, he assumed primary custody of both girls.

Snyder used a local agency, Adoptions From the Heart, to adopt her two children. At the initial information session she and her husband attended, she remembers asking: If you have a medical problem can you still adopt? The social worker right away said, "Yes, as long as

your doctor says you're physically and mentally able to take care of a child. We have cancer survivors and others going through different health battles — even people with biological children have health conditions." From that point, Snyder says, "I knew we would use this agency and that it was going to be possible!"

Adoptions From the Heart provided a timeline with steps for prospective adoptive families to follow.

"You go to classes about adoption, you meet the birth parents, you learn the laws," Snyder explains. "You have a home interview to be sure you have a safe environment to raise a child, then you put together a book about your life to be shown to the birth parents."

### **How to decide what to disclose**

Snyder felt close enough to her social worker to open up about her MS. "She was very reassuring, saying it was OK if I wanted it to be a part of our book, but if not — that was OK, too," she says. Ultimately, Snyder and her husband decided not to mention it. "Only because we didn't want someone assuming the worst-case scenario when reading about us," she says. Today, Snyder's family sees the children's birth parents once a year and exchanges emails and pictures, but the birth parents don't know their address or phone number, or that Snyder has MS. "We are building a friendship and one day our children will know everything about their birth story, and then they can choose who they tell about being adopted and who they tell about their mom having MS," she says.



**Andy Rafferty disclosed his MS during the adoption process as well as to his daughters. He says they are a huge help to him at home.** Photo courtesy of Andy Rafferty

Rafferty, by contrast, chose to disclose his MS. “It’s something I felt I had to be up front about in every way to protect Lily and myself,” he recalls. His lawyer asked a few questions and took notes, but it didn’t come up again at all in the legal process. “My own judgments on myself were way more harsh than that of the court,” he says. “It turns out they knew far better than I that you don’t need to be able to walk to love and support a child.” As far as disclosing his MS to his daughters, he told them on day one and continues to explain his condition at levels they can understand as they age.

Though Evensen hadn’t yet been diagnosed during Jocelyn’s adoption process, she believes she’d need to disclose it if the family were to adopt again. “I wouldn’t want there to be any secrets, especially if I were adopting an older child,” she says. Jocelyn thought Evensen was going to die when she was diagnosed, and it took several weeks to convince her that she wasn’t going anywhere anytime soon. “Kids need to know the truth so they aren’t caught unaware, especially those adopted out of the foster care system who may already have suffered some level of trauma, even if it was only the separation they experienced from their biological parents,” Evensen says.

### **Factors to consider**

The adoption process is no small hurdle, but a critical factor for people with MS to consider is whether they’re able to balance the needs of an infant or child with the needs and demands of their illness.

“Having a newborn is exhausting with not getting a lot of sleep,” Snyder says. She was lucky to have a support system in her husband, mother and mother-in-law. “They made sure I didn’t overdo it, including moving the baby clothes and changing table downstairs so I wouldn’t have to do the steps so much.” Washing bottles became her husband’s job since hot water is painful on the nerves in her hand. The family has learned to go to the park in the early morning before it’s hot to accommodate her discomfort with heat.

“We went to Disney and I rented a scooter because it was way too much walking,” Snyder says. “The kids loved riding with me. We saw everything we wanted to see and did everything we wanted to do.”



**Kat and Justin Snyder enjoy a family vacation with their son and daughter.** Photo courtesy of Kat Snyder

Rafferty admits to getting a lot of help from his mother and an “extremely fantastic village of help — it really does take a village,” he says. Though he’s able to work and enjoys full mobility, he often gets vertigo and can be suddenly overcome with fatigue. “These symptoms cause me to struggle with day-to-day tasks such as making dinner and doing dishes,” he says. “In both cases, the girls jump in and help out so I can lay low.”

Beyond coping with her own symptoms, Evensen has the additional challenge of parenting a child with special needs. “My daughter needs two parents helping to give her the highest level of success every day, and when I’m not at my best, I really struggle with the guilt of knowing I’m not carrying my share of the weight,” Evensen says. Her husband doesn’t complain, but she knows it’s hard on him to pick up where she leaves off.

“I really worry that I’m neglecting my family. Adjusting to our new normal has been harder than I anticipated when I was first diagnosed.” But then she adds, “My daughter is a blessing to our family — we would be incomplete without her.”

Evensen’s advice to prospective adoptive parents: “Be really honest with yourself and your licensing agency about your limitations. It’s easy to tell yourself that something won’t be too hard, but there’s no going back once you fall in love with an amazing child.”

Snyder adds, “Set up a great support system of family and friends to help and live in the moment. Do not let fears or unknowns scare you. You may not be able to run around the playground or play on the beach in the hot sun, but you can sit under an umbrella with a cooling vest at the beach, you can have a picnic lunch at the park, you can rent or buy a

scooter to go to amusement parks. Your child will love it regardless because of your love and support, and they will see how strong you are.”

**Aviva Patz is a writer in Montclair, New Jersey.**