

Growing up fast



Teens with MS face a unique set of challenges.

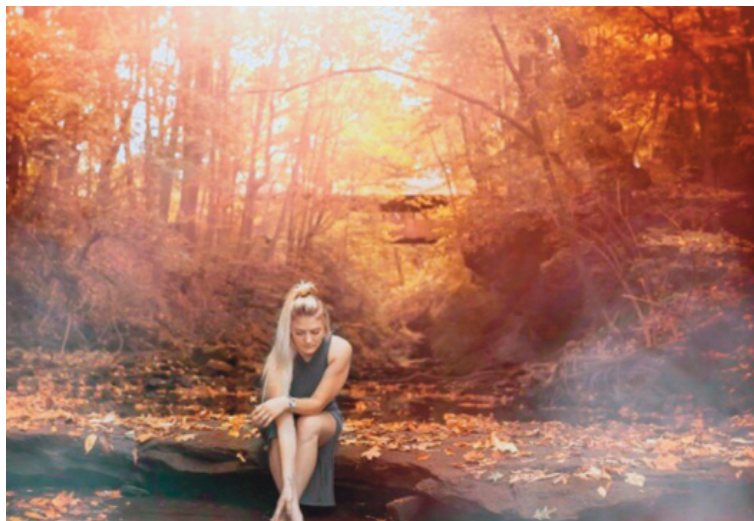
by Vicky Uhland

Kaleigh Napier started doing gymnastics soon after she learned to walk. Like every gymnast, she had her share of injuries as she grew older and her routines became more advanced. So she wasn't surprised when, at age 13, she began having shoulder pain and numbness in her hands.

Napier's doctor did an MRI on her shoulder and diagnosed a pinched nerve. But the pain didn't go away, and she began having migraines and paralysis in her legs. When she was 15, a neurologist conducted more MRIs and found a lesion on her spine and multiple lesions in her brain. Napier was diagnosed with multiple sclerosis.

Napier's grandfather has MS, so she was familiar with the disease. But she never expected to be diagnosed as a teenager.

"Being 15 and hearing the words, 'You have MS' took a huge toll on me. I watched my grandfather struggle with MS throughout his life and end up in a wheelchair," she says. "And here I was in high school wondering if that would be my future, too."



Living with MS has required Kaleigh Napier to “grow up fast.” She was diagnosed with MS at age 15. Photo courtesy of Kaleigh Napier

Emotional issues

Napier, who is now 19 and attends Kent State University in Ohio, is one of the approximately 8,000 to 10,000 Americans who have been diagnosed with MS before their 18th birthday. Although pediatric MS cases are rare, some studies estimate that 2 to 5% of all people with MS had symptom onset as a teenager or even younger.

The good news is that pediatric MS specialists say teens who begin MS therapies soon after their diagnosis rarely develop disabilities before their 20th birthday and can lead a relatively symptom-free life well into adulthood.

“There’s some evidence that people who get pediatric relapsing-remitting MS move to progressive MS slower than those who are diagnosed as adults,” says Tim Lotze, MD, associate professor of child neurology at Texas Children’s Hospital at the Baylor College of Medicine. “Maybe that’s because the ‘lucky’ ones who are diagnosed earlier start on treatment sooner.”

But while teenagers may have fewer physical MS symptoms than adults, they can have more emotional or mental issues. Adolescence comes with all kinds of angst. Add in an MS diagnosis, and the stress can skyrocket. “You grow up fast when you’re diagnosed that young,” Napier says.

Here’s what Napier, other teens, their parents and healthcare providers have learned about living with MS as an adolescent.

Difficulty with diagnosis

The number of children diagnosed with MS seems to be holding steady in recent years, although accurate data is lacking, says Brenda Banwell, MD, chief of the Division of

Neurology at Children's Hospital of Philadelphia and director of the hospital's Pediatric Multiple Sclerosis Clinic. But the awareness of pediatric MS has increased considerably among healthcare practitioners, meaning children are more likely to be diagnosed quicker.

There's also a growing amount of research focusing on pediatric MS.

- The Canadian Pediatric Demyelinating Disease Network has performed a comprehensive prospective analysis of children with a first attack of what may be MS and have published extensively on the clinical, biological and MRI features of MS in children.
- Doctors and scientists affiliated with 18 clinical centers throughout the United States have formed the [Network of Pediatric Multiple Sclerosis Centers](#) to study the causes and treatment of pediatric MS.

These and other studies show that while MS symptoms are similar in teens and adults, teens may be more difficult to diagnose.

"Teenagers may have more vague symptoms, like their back hurts, or they're having headaches or migraines with blurry vision, or they're having trouble walking," says Soe Mar, MD, director of the Pediatric Onset Demyelinating Diseases and Autoimmune Encephalitis Center at St. Louis Children's Hospital at the Washington University School of Medicine.

Couple those indeterminate symptoms with normal teenage stress, and Dr. Mar says some clinicians may think a teen with MS is suffering from physical symptoms that are due to psychological trauma rather than MS.

Another common misdiagnosis is acute disseminated encephalomyelitis (ADEM), which has symptoms similar to MS, but children with ADEM should have evidence of encephalopathy. ADEM is much more frequent in children than adults, Dr. Mar says, so clinicians may gravitate toward that diagnosis rather than MS.

Specific teenage symptoms

Onset of MS in children and youth is associated with a higher relapse rate and a higher volume of brain lesions, relative to early MS in adults. Pediatric MS occurs in the context of normal academic learning and during brain maturation. Of note, 30 to 40% of children with MS have cognitive impairment, Dr. Banwell says. This impairment varies from mild to severe, and mainly involves executive functioning, such as multitasking, organization, attention skills, processing speed and word finding.

About a third of teens with MS have emotional issues, such as depression or anxiety, Dr. Banwell says. But this mirrors the general population of teenagers, so it can be difficult to tell if MS is the culprit for mood disorders or if it's simply being an adolescent. Either way, mental health is an important facet of care for youth with MS.

"That's why I can't emphasize enough how important partnerships are with psychiatrists and

psychologists for teens who have MS,” Dr. Banwell says. These professionals can help teens and their parents sort out what’s causing depression or anxiety and how best to treat it.

Research shows that teenagers also tend to have more frequent relapses than adults, perhaps because they haven’t yet developed full nerve myelination, Dr. Lotze says. A 2014 study published in Multiple Sclerosis Related Disorders shows that children have 2.3 times more relapses than adults per year.

“The flip side is that children recover much better than adults from relapses,” Dr. Lotze says. “There seem to be less residual symptoms, maybe because myelin in children can repair faster. Or there could be something innate in the pediatric brain that can make new networks after an MS relapse.”

The importance of medications

While MS therapies can reduce disease activity in teens, the key is persuading them to consistently take their medications. “A lot of teenagers don’t think they need medications after they recover from a relapse,” Dr. Mar says.

Napier admits she felt that way. “When I was first diagnosed, I just wanted to be a normal kid and not take 20 pills a day,” she says.



Stacey Hirsch, diagnosed with MS when she was 14, found a treatment that works for her.

Photo courtesy of Stacey Hirsch

Stacey Hirsch, a West Bloomfield, Michigan, high school student who was diagnosed with MS in 2017 when she was 14, says it helped when her mom told her that MS was like having

diabetes. Stacey didn't know anyone with MS, but she did have classmates with diabetes and knew that their medications allowed them to do normal teenage things like taking gymnastics classes or going to camp.

So Hirsch religiously takes Tecfidera twice a day and has been rewarded with only one serious flareup in two years, following an ear infection. And her MRIs show no new lesions.

Only one medication, fingolimod (Gilenya), has been approved specifically for children over the age of 10. But pediatric MS specialists also use other MS therapies, following international consensus guidelines.

Despite their age, pediatric MS patients have a generally mature immune system, which matures very early in life, Dr. Banwell says. There's more concern about a medication's effect on the brain, which grows throughout adolescence. Dr. Lotze says there have been no randomized, placebo-controlled trials on MS drugs' effect on developing brains.

That said, Dr. Lotze notes that none of his teenage patients have had severe adverse events with the newer drugs. And Dr. Banwell says that, to date, data has not suggested a negative impact of MS therapies on the brain in children or teens with MS. In fact, in the fingolimod trial, treatment showed reduction in new lesions and a protective effect against brain volume loss.

Early-stage coping

While an MS diagnosis can be devastating for anyone, it can be particularly difficult for teens and their families. Parents struggle to accept the diagnosis.

"No one expects a child to be diagnosed with an adult disease," Dr. Banwell says.

One thing teens have going for them, though, is resilience.

Doug Roderus was an eighth grader in Ellicott City, Maryland, when he began losing vision in his right eye. An ophthalmologist recommended an MRI, and Roderus discovered he had MS.

"For the first 20 minutes I was freaking out. I was pissed, upset, scared," he says. "And then I thought, 'This sounds kind of familiar.'"

He had recently watched an ESPN program on a female runner with MS. "That gave me some peace of mind that everything could be OK."

Roderus, who was an offensive lineman on his middle school and high school football teams, approached his diagnosis like an athlete. He talked to a sports psychologist who told him that he really only needed to focus on his MS for the five minutes a day he injected his medication. "So for 23 hours and 55 minutes, I live life like I don't have MS," Roderus says. "I realized if I found the right medications, exercised and ate right, I could have control over my MS."

Now, at age 18, “I kind of view it as I’m living the life I would have had if I didn’t have the disease,” he says. “I’m staying positive that my MS won’t affect the rest of my life in a big way.”

Freaked-out parents

Roderus’ diagnosis wasn’t as easy for his parents, though. “My husband, John, and I were absolutely bawling when the doctors told us,” says Roderus’ mom, Sarah. “We knew we had to stick together and be there for one another, just as much as we are for Doug. Staying open about our feelings would help us deal with this together.”

But then Sarah began reading medical journal articles about MS, which caused her to wake up screaming from nightmares about what could happen to Doug. She realized she had to stop and focus on being a mom, leaving the medical journals to the doctors. And although it’s been four years since Doug’s last relapse, Sarah and John never stop worrying that he’ll have another.

Pediatric MS doctors say this isn’t unusual. “Sometimes the parents can be more of an issue for a physician than the child,” Dr. Lotze says. “Teenagers have a sense of invulnerability, so their MS can fade into the background. That’s not the case for the parents.”

Dr. Banwell said a colleague recently completed a study showing that the impact of a child’s diagnosis with MS is so substantial for parents that they can end up using more healthcare resources than their child.

Hirsch’s mother, Julie, believes a strong support system is key for helping parents cope with their child’s disease. “After Stacey was diagnosed, I quickly found the PMSA (Pediatric Multiple Sclerosis Alliance) group on Facebook. Connecting with other parents of children in similar situations to ask questions to, and get support from, was invaluable.”

The Hirsch family also formed a Walk MS team with other Detroit-area families affected by MS. And they serve on the board of directors of [Families Fighting Against Multiple Sclerosis](#).

“When you have a child who has such a serious disease, you have to have a strong team supporting you,” Julie says. “You cannot do this by yourself.”

Overcompensating teenagers

While parental stress about their teen’s MS diagnosis is understandable, it can create additional emotional issues for the child.

“This is all happening while kids are at the age of trying to get independence from their parents,” Dr. Lotze says. “I’ve seen parents collapse around kids and smother them.” That’s why pediatric MS specialists try to talk directly to teens. “A physician can advocate for children who may not be able to express themselves to their parents,” he says.

Teens may also avoid talking to their parents about their disease because they don’t want to

worry them.



Emily Blosberg founded Oscar the MS Monkey, an organization that helps kids and teens with MS. Photo courtesy of Emily Blosberg

“I look like a different person when I relapse. I look so sick, and I know that upsets my parents. I would talk to my mom about it, but I don’t want to make her even more upset,” Napier says. “My dad calls me constantly to see how I’m feeling. It breaks my heart to see how worried they are. I wish there was a way to let them know I’m going to be OK.”

Teenagers can also hide their feelings for other reasons. When Minneapolis resident Emily Blosberg was diagnosed with MS at age 15, she blamed herself.

“I was getting all this attention because of my symptoms, and frankly I was enjoying it,” Blosberg says. But it took 14 months to get a diagnosis, and the initial attention subsided. “I started wishing that something would happen again so I would get more attention,” she says. “And then I found out I had MS. I felt like it was my fault even though deep down I knew it wasn’t.”

Blosberg, who is now 22, says it took a couple of months to stop feeling devastated that she brought her disease upon herself—and to admit those feelings to her family and friends.

Dr. Lotze says a key to breaking through these types of communication barriers is for parents to “not hide anything from the kid from day one. Parents need to make a plan on how to talk to their son or daughter.” A therapist can also help the whole family, including anxious or resentful siblings, open lines of communication.

School relationships

Family relationships aren’t the only ones that suffer when teens are diagnosed with MS. Teens can face misunderstanding or even bullying about their disease.

Blosberg missed all of eighth grade due to symptoms like numbness and tingling throughout her body, eyesight issues and skin so sensitive that even wearing clothes was painful.

“I didn’t want to tell anyone about my MS because I didn’t want to be treated differently,” Blosberg says. “But people started spreading rumors. They called me ‘teacher’s pet’ because I turned in assignments late, or I ate lunch in the nurse’s office so I could rest. And I couldn’t create any relationships because I kept missing so much school.”

Blosberg finally decided she needed to counter the rumors by sharing her story. “I made a video so the entire school would know I have MS. I said, ‘I’m not looking for your sympathy. I’m looking for your support.’” The video stopped the whispering and helped her make friends. So did a part-time job as a high school paraprofessional. “I did it for the social aspect rather than the money,” she says. “MS can be such a lonely disease.”

Blosberg also got involved with the Teen Adventure Program, a summer camp run by the Lourie Center for Pediatric MS at Stony Brook Long Island Children’s Hospital. “It was life-changing. I was surrounded by teenagers with the exact same thing as me, and no one had to explain anything,” she says. She and her family have since put on their own camps and help provide transportation to MS camps through Blosberg’s organization, Oscar the MS Monkey. Through donations, the organization sends care packages containing sock monkeys to children with MS, as well as gives each Teen Adventure camper their own sock monkey. “My message is, it’s OK to not be ‘normal.’ You can create your own normal,” she says.

An A for effort

To add to the relationship problems with classmates, MS-related cognitive issues and hospitalizations can play havoc with schoolwork.

That’s why 504 plans are so important, says Julie Hirsch. These plans, which are covered under section 504 of the U.S. Rehabilitation Act, are for children who have any type of disability that interferes with learning in a general-education classroom.



Stacey Hirsch (far right) and her family members, Ron, Rachel, Julie and Melanie Hirsch (from left to right), at a 2018 Walk MS event. Photo courtesy of Stacey Hirsch

A 504 plan is created by the parents, teachers and school administration to provide accommodations for a student's special needs. Generally, a student only needs to submit a letter from a guardian or doctor to qualify for a 504 plan.

Hirsch is a straight-A student, but she's learned that she can have scholastic limitations because of her MS symptoms. Her 504 plan includes things like extra time for ACT testing and permission not to take gym class when she's feeling heat sensitive.

504 plans can also help students make up coursework if they miss classes due to MS symptoms. The plans can specify that someone takes notes for a student who has hand numbness or writing problems. And they can address fatigue issues by rearranging class schedules or exams.

Learning how to be different

After Napier was first diagnosed, she bemoaned how MS made her different from her classmates. "I really missed who I had been before. I hated being in so much pain. I hated missing out on being excited to have your crush take you to homecoming. I was always dwelling on not having a normal teenage life."

But eventually, Napier pulled herself out of the fog. "I told myself that it's OK to not be OK. I'm going up this hill called life, and MS is just one more thing in my backpack to make me stronger," she says.

Like Hirsch, whose MS diagnosis has sparked interest in becoming a neurologist specializing in pediatric MS, Napier's diagnosis has also affected her career path. She's majoring in entrepreneurship and has started a business helping people with MS and others plan their diets and workouts.

"Now I can see the blessings of being diagnosed with MS as a teenager," Napier says. "I have the opportunity to show others that you can get through anything."

Vicky Uhland is a writer and editor in Lafayette, Colorado.

Learn more about [how MS affects children](#).