

EVERY DAY
A STRUGGLE,
EVERY DAY
A GIFT



Caring for twin sons with autism has dominated **Curt and Ana Warner's** lives for two decades. In a "blisteringly honest" new book, they tell their family's story in a way that they hope will help other families—and, in the telling, themselves.

BY **LORI SHONTZ**
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PHOTOGRAPHS BY
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WHEN THE INVITATION APPEARED in his inbox, Curt Warner ignored it. The National Autism Conference was holding its 2013 annual event at University Park, and the organizers wanted **Warner '83 Lib** to speak about his family. He loved his boys so much—but how could he talk about them? For a lot of reasons, that just wasn't the kind of thing Warner or his wife, Ana, had ever done.

At first, especially, they didn't know what to say. As toddlers, their twin sons Austin and Christian were nonverbal and energetic and aggressive, far more difficult to handle than their older son, Jonathan. Doctors couldn't explain why the boys would eat books or string or fabric, or why they'd cry and hit and slap and bite. Shoppers and passersby were judgmental when the Warners took the boys out and a meltdown ensued—whether through words or nasty looks, it was clear they blamed bad parenting.

The boys weren't diagnosed as severely autistic until they were 5. The Warners then tried a variety of therapies and treatments; eventually Ana began cooking every meal they consumed—gluten-free, dairy-free, no preservatives, organic everything—because it consistently seemed to help the boys' behavior. Still, they were a challenge. At one point, Curt and Ana had to sleep in shifts to monitor the boys, and for a while Ana homeschooled them.

As a three-time Pro Bowl running back with the Seattle Seahawks from 1983–89, Curt would have been a regular

attendee at team events after retirement. But he rarely showed. He couldn't. He didn't leave his family except to work at the car dealership he owned in the suburbs of Portland, Ore.

When the boys' behavior calmed after puberty, Curt didn't want to relive what they'd been through. It's never been a 24/7 job to take care of the boys. Says Curt: "It's 25/7." He and Ana had automatic locks and alarms installed on every door and window to make sure the boys didn't leave, because they would have no idea how to get back. Curt learned to hang drywall, because the twins so frequently kicked and punched holes in walls. He rushed home in a panic one day when Austin, then 12, thought he was Pinocchio inside the whale, and he had to light a fire to get out—and he somehow found matches and ended up burning the house down. Everyone got out safe, but the Warners lost everything.

And so, when that invitation hit his inbox back in 2013, Curt at first didn't respond. He couldn't envision speaking about those days; he feared doing so would result in one of two things. First, that perhaps people would think he was complaining; he couldn't abide that. He loves his boys, and in many ways, he believes he has been blessed. And second, the biggie: Curt didn't think he could make it through a talk without being overcome by emotion. He didn't want to cry.

But then the Warners thought about how little they knew about autism when the twins were diagnosed, and how the examples of autism in popular culture—the high-functioning genius, the awkward savant—didn't reflect their experience. And they figured they could visit their older son, Jonathan, who at the time was a freshman wide receiver for the Nittany Lions. So they came.

Their talk (you can find it on YouTube) was raw, unpolished, and compelling, in part because Curt, the College Hall of Fame running back and star of the Nittany Lions' 1982 national championship team, really did choke up. When he couldn't continue, Ana simply took over until he could speak again. And the response made the Warners realize that perhaps they needed to tell their story. To help other families in the same situation, yes. To broaden the public's conception of what autism is, yes. But also for themselves.

And that's how the Warners ended up writing a book, *The Warner Boys*, which will be published by Amazon in December. Their coauthor, Dave Boling, calls the book "blisteringly honest," and that's an understatement. In it, the Warners, isolated and private for so long, open up about everything, from their darkest and most frustrated times to the



GLORY DAYS

Warner's office includes select mementos from his playing days, when he was a two-time All-American at Penn State and a three-time Pro Bowler with the Seattle Seahawks.



BEN LIEBENBERG/AP IMAGES (2)

moments of humor and joy and love. “I think initially it was therapy for us to a certain degree,” Curt says. “But at the same time, I’m thinking to myself, ‘You can’t make this up, what we’re experiencing.’ So let’s put it down on paper and—knowing that there are other families out there who are dealing with it—see if we have something to talk about.”

IT’S A FRIDAY MORNING IN MID-MAY, AND it’s situation normal at the Warner home in Camas, Wash. That means three dogs, sized small, medium and large, are romping around. Austin, who has just returned after one of his CrossFit workouts, is yelling “Hello” and “Happy Mother’s Day” before heading upstairs to do something on the computer. Christian is wandering around the kitchen, wondering what’s next on the daily schedule.

“Mama!” Christian calls. “Mama! Mama! New floors?” He stuffs his hands into the waistband of his jeans.

“Nice hands, Christian,” Ana says. “Nice hands.” Christian removes his hands from his jeans. “We’ll get the new floors on Monday,” she continues. “I’ll do your schedule later.”

“Now?” Christian asks. “Now?”

“Not now. Later.”

Christian walks off, and Curt laughs: “Mr. Christian’s got to have a schedule.” The homemade schedule form, which the Warners print by the dozens, has space to record a specific time for each part of the daily routine: wake up, shower/clothes on, breakfast, lunch, dinner, shower/pajamas on, and bedtime. There are eight other lines to add additional activities—Austin’s work schedule, perhaps, or a community outing, which is labeled “fun.” Or, in this case, “new floors.”

“His day needs to be structured,” Curt says. “It has to have a regimen to it. He doesn’t like surprises—it stresses him out. But if you can see the calendar ...”

Ana completes the thought: “The level of anxiety goes down.”

If Ana isn’t finishing her husband’s sentences, Curt is finishing hers. Twenty-four years of caring for the boys, as they always call Austin and Christian, plus 25-year-old Jonathan and their adopted daughter, 12-year-old Isabella, has forged them into a tight-knit team. That’s the first thing Boling, their coauthor, noticed. He had covered the Seahawks for a Tacoma newspaper for more than 20 years, but he didn’t know Curt, whose last year with the team was Boling’s first on the beat. (He’d always assumed that the Warners just wanted to live a private life—“off the grid.”) But when Curt asked the Seahawks

A TIME TO LEARN

The National Autism Conference draws experts, educators, and families to University Park each summer for the latest research and perspective.

Practical assistance for teachers, therapists, medical professionals, and parents is the primary goal of the National Autism Conference, held annually at University Park. The conference, a collaboration between Penn State and the state education department’s Teaching and Technology Assistance Network (PaTTAN), draws some 1,500 attendees annually, most recently at the 22nd annual conference in August at the Penn State Conference Center.

Mike Miklos, co-lead for PaTTAN’s Autism Initiative, says that even as the conference maintains its focus on “highly technical but accessible” education, it has expanded to welcome both parents of children on the spectrum, and the children themselves. The

annual Children’s Institute is a “camp-like experience” at which kids get to learn and perform a musical, and coincides with a special Penn State Science U. camp geared toward high-school age campers.

The conference, where Curt and Anna Warner (below) first told their family’s story in 2013, also provides valuable training for students in Penn State’s special education master’s program. Special education professor David Lee says his students attend sessions with select conference speakers, giving them access to “top researchers and practitioners in the field,” and that the collaboration with PaTTAN benefits all involved: “We’re a land grant institution. This is the kind of work we should be doing.” —RJ



A “25/7” RESPONSIBILITY
While Isabella keeps herself busy, Austin, left, and Christian demand constant attention.

PR department to recommend someone who could help with the book, he got Boling’s name.

They met in person, and the Warners began telling their story. Boling listened for less than 15 minutes. He didn’t need to be sold on the project. He was in, and he already had a vision. He told them, “This isn’t a book about autism, or about challenging parenting. It’s not a book for Penn State fans or about Penn State. I see this as a great love story.”

Boling remembers that both Warners laughed. They told him, “That’s what we think it is, too.”

Curt met Ana in the late 1980s, when he was the Seahawks’ star running back. He walked into a downtown department store one day and noticed Ana, who had moved to the U.S. from her native Brazil at 27 and was working as a fragrance model—and who had a less-than-positive impression of football players. But Curt, she sensed, was different. With an assist from one of Curt’s friends, he and Ana quickly connected. They got engaged on Valentine’s Day 1990, just as he was in the process of retiring.

“The timing of Ana’s coming into my life was perfect,” Curt writes in the book. (He and Ana alternate writing

duties.) “I needed her; I just didn’t know how much. Back then, nobody prepared players to handle the twilight of their career. That’s why so many players got into deep financial trouble and had such a hard time dealing with the transition to life after the NFL. Here’s how it goes for a lot of players: All of a sudden, you’re not a professional football player. You have to be able to create a new identity—at age 30. When you’re not on the field, with your teammates every day, you lose touch with those close friends. And all that camaraderie that was so rewarding is gone. Ana helped me through those difficult transitions.”

Soon Ana was pregnant, and the Warners were thrilled. As the due date neared, the doctor needed to determine whether a Caesarian section was necessary, so they scheduled one final ultrasound on the day Ana’s family was flying in from Brazil. Then the doctor said they needed more tests. And then he told them that the baby had died. Shocked and grieving, Ana delivered their stillborn son, Ryan, that night.

“I had seen how strong Curt had been through the end of his football career, how squared away he was emotionally, and how he dealt with physical pain without ever complain-

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A TRUE TEAM EFFORT
Writing a book about their family's challenges brought Ana and Curt closer together.

ing," Ana writes in one of her chapters. "I knew he was made of some kind of inner steel, but this loss affected him so deeply. That night in the hospital, after the nurses had taken Ryan away, it seemed like the one thing in our lives we could count on was that we were together, there for each other. It was a certainty we each could carry with us. Our love for one another was forged and tempered to an even greater strength and depth through the experience."

They needed the strength. Ana endured several more miscarriages before giving birth to Jonathan, whose name means "God's gift." Eighteen months later, the twins were born. Several months after that, Ana was diagnosed with postpartum depression. And then the twins began acting in a way that the Warners describe in the book as "menacing," but no doctor could determine why.

"I've heard that parents often feel a sickness of their own when their children are hurting," Ana writes. "I know I did. Every day that the boys dealt with these troubles was a day we hurt along with them. The doubts and confusion started consuming our lives."

When the Warners finally got the diagnosis, they didn't know what to think. The only thing they knew about autism was the Dustin Hoffman character in *Rain Man*, and they didn't think the boys' behavior resembled that. They went home and logged onto the internet, looking for a way to fix it. They never found one. It didn't exist.

"Especially in the first five years, when you're going through the diagnosis, that's intense," Curt says. "She's

thinking, 'Let's fix it,' I'm thinking, 'Why can't you fix it?' That took us a while to figure that out. Then we got on the same page—or at least, I got on her page."

Ana laughs.

"To be honest with you, every day is a struggle," Curt says. "Because you get mad. You're disappointed. Every day. So you pray ..."

He tails off, and Ana picks up the thought: "A lot."

A **S THE WARNERS ARE TELLING THEIR** story at their kitchen table, Austin walks in. "Laptop on," he yells.

Curt talks him out of this. Austin has been on the computer upstairs, and Curt doesn't see any reason that Austin needs to be on this one, too. Ana backs up her husband: "No. Gotta do that later."

Austin moves to the couch and begins counting from one to 22. Then he wanders to the kitchen, sees a loaf of bread and pulls it apart, stuffing a chunk in his mouth and heading upstairs with the rest. "No," Ana says. "You're not taking that upstairs. I'll cut you a slice. How's that?"

"Sorry for the interruption," Curt says. It's an apology he's made repeatedly. "It's just part of the process around here."

Ana slices the bread. Austin waits. "Mom!" he yells. "Happy Mother's Day!" And then he wanders away again.

The scene is exactly what Boling witnessed on a weekly basis as he did Skype interviews while he and the Warners worked on the book. Each call unfolded the same way: Curt

and Ana would be in a room together, answering questions, and every couple of minutes Austin would wander into the room and start yelling, the repetitive vocalizing that's a common symptom of autism. (A typical phrase: "Hi Dave!") Ana would say, "Use your words" and pat Austin's hands to soothe him, and eventually Curt would take Austin into the next room until he calmed down. And then a couple of minutes later, Christian would come in, and the cycle would start again—this time, with Curt continuing with the interview and Ana leaving the room to deal with their son.

"It was this beautiful teamwork in action," Boling says. "I would get off the phone, and I'd be exhausted. And I would have no idea how they did it. It was a master class, a TED Talk in extreme parenting. It was really something to see."

Ana impressed Boling with her eloquence. When something became too much for her to talk about, she told him she'd think about it and email him the answers. Curt had a harder time, and Boling soon realized why. "It's not that he's aloof or anything—it's because he doesn't ever want to sound like he's complaining," Boling says. "It's the sense of pride he developed as an athlete, that helped him be the athlete that he is. I had to pull it from him."

And that wasn't just the details of daily life in the Warner family, or the twins' particularly difficult teenage years. Boling pushed Curt to recount his days growing up in rural Wyoming, W.Va.: being adopted by his grandparents at birth, growing up in a house that didn't have an indoor bathroom until he was in middle school. Curt preferred to focus on the joyful stories of the life he and his family had built: about the Disney movie nights, about how Ana, who'd had it with watching the same movies over and over, donated their entire collection to Goodwill, and how she went back the next day to buy back as many as she could because the boys were so upset. (The twins still yell "VHS" to make their displeasure known, which makes both Curt and Ana laugh.)

He was less comfortable relating the bad days with his children. "He was real cautious," Boling says. "But at the end, he realized what a catharsis it was for him, and I tried to use some of that in the book."

The family is focused now on the twins' future. Austin and Christian graduated from high school three years ago, at age 20, but that wasn't an academic achievement. It just meant that they aged out of the educational system. Both have had part-time jobs at a company that manufactures silicon-wafer semiconductors. Austin was a production assistant, scraping labels off boxes, handling some shipping information and doing some cleanup. (He liked the paycheck,



The Warner Boys: Our Family's Story of Autism and Hope, will be released by Amazon's Little A publishing imprint on Dec. 1.

mostly to buy Disney videos.) Christian works in the uniform distribution center, working the computer and scanning uniforms. (He doesn't care much about the money, but he likes the social aspect of the job.)

But that's not a plan for the rest of their lives, a reality that thousands of families with autistic adults are struggling with: According to a recent CDC report, some 50,000 teens with autism age out of the education system each year. Says Ana, "There's no talk about housing. Employment. And what's going to happen when the parents pass away."

That last point, for the Warners, is particularly emotional. "How do you tell them?" Curt wonders.

Adds Ana, "It's like, 'I've got to live forever, because what's going to happen to them?'"

The Warners' answer is this: They are building a home for the twins at the Trellis Center in Ellensburg, Wash., a non-profit ranch and farm that supports adults with disabilities. One day, the boys will live in the house with two others—and each will own 25 percent of the house, free and clear. They'll be cared for by live-in aides and counselors and interns from nearby Central Washington University. In a particularly Pacific Northwest touch, the Trellis Center includes a CSA with an organic farmers-market cart.

"We want them to have a life," Curt says.

It's an expensive proposition, even for someone who played eight years in the NFL and who now owns an insurance agency in Portland. (According to one academic study, the cost over a lifetime to raise one adult with an intellectual disability is \$2.4 million.) That's part of the reason for the book, too, and the boys know that. Says Ana: "They say, 'December first, book. And house.'"

Since speaking at Penn State five years ago, the Warners have told their story more frequently. They'll likely do it again, repeatedly, when the book is published. And Curt has joined the board of the Autism Society of America. "It's getting easier," Curt says. "But it's still somewhat uncomfortable at times"

Ana jumps in. "We've been so isolated that I became more of an introvert," she says. "So to get out and be talking to other people, that's kind of"

Both Warners pause.

"It's kind of hard to explain," Curt says, finally.

Ana picks up the thought. "That's why we wrote the book," she says. "It explains." ♥

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