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DEFINING GRACE

8-year-old's passion gives her a sense of self after undergoing brain surgery to treat a neurological disorder

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Everything Grace Lorton does smacks with a sense of purpose and order. You can tell as much from the notebook she decorated. It sits atop her desk at Mayflower Mill Elementary School.

Boldly colored M&M stickers march across the bottom of the cover while a ribbon of animal paw prints lines the left side. Minions, owls, peace signs, ponies and flowers — some of which are symmetrically arranged — fill in the middle. A blue feather is glued to the side, artistically titled toward the top corner and surrounded with sparkling butterflies.

The third-grader's artistic and analytical sides live hand in hand. Ask about the characters she's played onstage at Myers Dinner Theatre, and Grace's thoughtful green eyes, set below long waves of brown hair and above a splash of freckles, sparkle with familiarity as she tells their stories.

Jane, an add-in character in "Annie Warbucks," is a little girl who doesn't know if her parents are alive after they disappeared. Nellie finds herself confused as Annie Oakley's assistant in a shooting match in "Annie Get Your Gun." And then Grace has multiple roles in "Chitty Chitty Bang Bang": Edison the family dog, one of the kids in the sewer under the castle and a part in some of the ensembles.

Grace's eyes light up with a firm sense of confidence when she tells you she'd like to be a mechanical engineer someday — not a surprise considering her favorite subjects are math, reading and science.

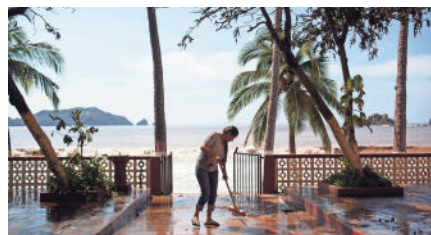
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“If there's something wrong that's going (on) in your life, and you don't like it, you can just break out of that feeling and then become someone else.”

GRACE LORTON



PHOTOS BY JOHN TERHUNE/JOURNAL & COURIER
Grace Lorton plays Edison the dog in "Chitty Chitty Bang Bang." Caden Sixberry, from left, Preston Dildine and Alivia Williams also act in the Myers Dinner Theatre production.



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Agency sees rise in homeless families

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A sexual assault last December pushed Shanika Wilson, a Lafayette mother of four children, over the edge.

It was the tipping point, she said, on a life already fraught with past sexual abuse, mental illness and domestic violence.

It sent Wilson spiraling back into depression.

She couldn't sleep. She worried about losing her children. She had thoughts of suicide.

Wilson lost her job as a certified nursing assistant and couldn't pay her rent or utilities. For several months, she and her children stayed with friends because the family couldn't stay in Wilson's Lafayette apartment, which had no electricity.

Her landlord evicted her in July.

"I didn't know if I was going to be able to take care of my children," said the 28-year-old. "My children are my world. They are the only family I have."

Wilson has struggled with homelessness since moving to Lafayette seven years ago to escape her abuser.

Wilson's predicament, however, is becoming more common.

The agency that now provides her housing, Lafayette Transitional Housing Center, has seen a 65 percent increase in the number of homeless families it has served this fiscal year.

In 2014, 107 families received homeless services or were housed through the nonprofit compared to 176 this year.

"Homelessness is usually a very

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GRACE

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And Grace's eyes assume a straight-forwardness when she chronicles her journey through the surgery she had last year to treat her Chiari malformation, a neurological disorder caused from a structural defect in the back of the brain and skull. She calmly articulates the details of the symptoms, tests, hospital visits and recovery.

"Grace is a really tough kid. I don't think you understand how tough a 7- or 8-year-old can be until they're put into a situation like this," said her mother, Tiffany Lorton.

When the third-grader talks about her condition, that composed sense of purpose shows through even as she admits her fears.

"When I was going in (to surgery), I'd never been that scared before. You know, for a first surgery, a brain surgery is like, 'Wow, it's a big surgery,'" Grace said.

"I didn't know what at all was going to happen. ... Were they going to have to draw my blood a lot or a little? Or even at all? Are they going to give me lots of medicine? Am I going to throw up? All these things I was just worried about. What happens if the surgery goes wrong?"

A star is born

Acting became a constant in Grace's life before the Chiari diagnosis set her and her family's life on the course of the unknown.

Her grandmother signed her up for lessons at Myers Dinner Theatre when she was 6 years old, and Grace quickly took to the craft even as she confronted its challenges.

The Hillsboro theater is rooted in the Christian beliefs of its founders, Donna and Richard Myers, and champions a family atmosphere, said Michael Moyer, a co-producer at the theater and one of the partners in Revolution Productions, the company that puts on shows at the location. The theater enveloped Grace into a culture characterized by positive productions and home-cooked meals before shows.

"I really like it because I make a lot of new friends from it," Grace said. "Well, the first show, you don't know hardly anybody if nobody else that you know acts. But at first you get to know everybody and ... then you know some of the people if they audition or if they came to one of the shows to watch you and you met them."

From early on, Grace's teachers focused on improving her volume, assertiveness and spontaneity on stage.

When she first came to lessons, Moyer said, hearing what she said was difficult even for those sitting next to her. Breathing exercises boosted her voice projection, and Grace counts their effect on stage presence her most important lesson so far.

Improvisational games — similar to those on the famous show "Whose Line is it Anyway" — improved Grace's ability to think on her feet and use her instincts, Moyer said.

"She is a very analytical and very careful thinker, and, you know, she wants to be right," Moyer said. "And it's getting her to understand that when you're on stage, you're playing somebody else and you're creating that, so probably whatever your first instinct is, is the correct one."

As she worked on these lessons, Grace's natural ability showed through, and she soon acted in her first production at Myers.

Her excitement and eagerness to learn stood out to her teachers. Grace didn't let on that she suffered from headaches or any of the other Chiari symptoms, Moyer said. He didn't know anything was physically wrong until her family told him of her diagnosis.

Diagnosing the disorder

Grace doesn't remember not having headaches. They were simply part of her existence.

That changed on Christmas Day in 2013. A then 7-year-old Grace went to retrieve her coat at her grandmother's house, and she didn't return for a while. When Lorton asked what took so long, she told her mom she had a bad headache and had to lay down for a bit.

Lorton's nursing background kicked in, and she began questioning Grace. Her daughter's answers pointed toward a neurological issue. Grace had been experiencing severe headaches, tingling and numbness in her limbs, and dizziness.

Suspecting a Chiari malformation,



JOHN TERHUNE/JOURNAL & COURIER

Grace's grandmother signed her up for lessons at Myers Dinner Theatre when she was 6 years old. "I really like it because I make a lot of new friends from it," Grace said. As she worked on her lessons, Grace's natural ability showed through, and she soon acted in her first production.

“

When she was able to get back (and act) and really be able to focus on that, I think that really helped turn her focus from, ‘OK, well, I got through that. I’m good to go. Now we can move on to post-surgery Gracie. I can get on with my life.’ ”

TIFFANY LORTON,
Grace's mother

her pediatrician recommended an MRI. The first results didn't mention the condition, but a second reading showed Grace's cerebral tonsils extended 16 millimeters past where they should have been. The diagnosis for was positive for type I.

In this condition, the cerebellum — the bottom portion of the brain — descends below the skull and into the spinal area, which affects the flow of cerebrospinal fluid that travels through the brain and spinal chord, among other complications, according to Conquer Chiari, a nonprofit organization that sponsors research and educates those affected by the disorder.

The causes aren't clear. Most organizations and neurosurgery departments say people are born with Chiari — whether it is genetic or occurs because of abnormal fetal development is up for speculation.

Most of the time, doctors identify Chiari incidentally, said Dr. Francesco Mangano, a pediatric neurosurgeon who operated on Grace at Cincinnati Children's Hospital Medical Center. Some might be athletes with a minor injury or concussion, he said, and Chiari is identified when they undergo a scan. He said the clinic sees a few hundred patients every year whom he would diagnose with type I, and of those, it recommends surgery for 20 to 25 percent.

"If you get enough compression on the back of the spinal cord, you can also have some sensory symptoms that go along with that," Mangano said. "So we start hearing about numbness and tingling in the hands, difficulty with balance, difficulty with swallowing."

Lorton and her husband met with neurosurgeons in Indianapolis, Chicago and Cincinnati, trying to deduce whether

Grace should have surgery. Because of Chiari's varying nature — some patients don't show symptoms — the decompression operation is not always the answer. If Mangano is unsure of whether a patient should have surgery, he said he waits to better assess the headaches and other symptoms.

To help determine this, Grace tallied the quantity and severity of her headaches daily. She estimates having experienced, on average, 15-20 headaches per day that could last up to a few minutes each and hover around four to six on a 10-point pain scale.

Over time, her symptoms worsened and she began losing balance, said Lorton, who chronicled the experience on her blog. So Grace went in for surgery in July 2014. Lorton and her husband would take turns sleeping in the room with their daughter since there was space for only one person.

"All of your knowledge and comfort around health care goes out the window when you're dealing with your own child," Lorton said.

"You're no longer a nurse when you're sitting in that pre-op room getting ready to send your child into surgery."

Rough road to recovery

Surgery to treat Grace's type of Chiari malformation is aimed at relieving pressure on the spinal area. When he operates on patients, Mangano makes a small incision from the bottom of the skull to the top of the neck behind the hairline. He then removes about 2½ centimeters of the back of the skull and part of the ring the skull sits on before thinning out the dura, which covers the

IF YOU GO

» **What:** "Chitty Chitty Bang Bang"
» **When:** Noon with meal Wednesday and Saturday. 6:30 p.m. with meal Friday and Saturday. Through Nov. 7. Call to be sure of specific dates.
» **Where:** Myers Dinner Theatre, 108 Water St., Hillsboro
» **Cost:** \$38 adults, \$27 students with ID with meal; \$21 without meal
» **More information:** Call 765-798-4902 or visit myersdt.com.

ABOUT CHIARI

Chiari malformation is a neurological disorder caused by a structural abnormality. The cerebellum descends below the skull and into the spinal area, which affects the flow of cerebrospinal fluid that runs through the brain and spinal chord, among other complications, according to Conquer Chiari, a nonprofit organization that sponsors research and educates those affected by the disorder. While most organizations and neurosurgery departments say that people are born with the condition, the exact cause isn't known. Symptoms include headaches, dizziness, loss of balance, trouble swallowing and numbness in extremities, although some people with the disorder don't experience them, according to the organization. About one in 1,000 people has the disorder, and about 300,000 live in the United States.

AT JCONLINE



Video: Grace talks about her experiences onstage, where "everybody's having fun."

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GRACE

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cerebellar tonsils and spinal cord. If the tonsils put compression on the brain stem and spinal cord, then Mangano can shrink them.

After that, he sews in a dural patch that gives the patient more room at the back of the skull. During surgery, Mangano said the team monitors the brain stem and spinal cord to ensure patients don't experience neurologic dysfunction. Often only one surgery is necessary, Mangano said, but sometimes symptoms come back and another operation is needed.

Grace still remembers coming out of the four-hour surgery.

"I woke up and my parents were sitting on a bench that was ... in front of me," she said. "And I woke up and I didn't know if I was, like, crying in my sleep because I woke up, and I heard myself whimpering. And I remember right next to me was a nurse. He was saying 'Shh, shh, shh, shh, it's OK.'"

In the days, weeks and months following the surgery, Grace experienced the effects of major surgery. Moving her head was extremely painful, she said. Her energy wore out quickly. She had to stay on pain medication and survive more headaches, though their quantity and intensity had decreased.

But Grace's recovery went according to plan, and over the next several months, her neck muscles regained strength. She was able to start school as scheduled, missing a few days here and there and occasionally going home early, Lorton said.

To stave off headaches, Grace spent time in the school nurse's office as needed. Lorton sent along a chart detailing possible symptoms and how to manage them. Grace stayed off the school bus and ate lunch in a quiet area to avoid the noisy environments that often bother Chiari patients. To keep her neck from kinking, Grace used a laptop table to do schoolwork at her desk. And she didn't wear collared shirts.

Thanks to the operation, Grace said she's down to three headaches per month that last about 30 seconds each.

"I actually didn't know if this was normal because, you know, I'm not used to *not* having headaches," she said.

Before and after the operation, keeping patients from hyperextending their necks is imperative, Mangano said. That means bounce houses, trampolines and contact sports are out until the decompression is deemed successful.

But Grace still craved what everyone her age does: something fun to keep her mind and body busy, something she could identify with.

Getting on with her life

About six weeks after her surgery, Gracie returned to acting lessons, something she could de-

pend on to come back to herself — the person she was apart from Chiari.

But returning to acting meant starting over again on almost everything, Moyer said.

They warmed up with games and covered what Grace had learned in her first lessons. Since she was instructed to breathe naturally after surgery, she had to forgo for a while the all-important exercises that boosted her volume.

"She was able to go to lessons — they'd take it easy, do her breathing exercises, get her diaphragm back up and running. And then she could start doing some of the dancing and choreography moves, and that really helped, you know, rebuild that core and even her neck muscles," Lorton said.

Despite limitations from the recovery process, acting provided the mental, psychological and physical stimulation she craved. Grace also reunited with her acting buddies.

"When she was able to get back (and act) and really be able to focus on that, I think that really helped turn her focus from, 'OK, well, I got through that. I'm good to go. Now we can move on to post-surgery Gracie. I can get on with my life,'" Lorton said.

In Grace's estimation, acting provides an excursion into a different situation.

"If there's something wrong that's going (on) in your life, and you don't like it, you can just break out

of that feeling and then become someone else and then you just break into that life for a while," Grace said.

Slowly, the family has worked back into the busy, familiar schedule. Running lines before breakfast and doing schoolwork on the bus home. On the drive to Hillsboro, singing along to the production's soundtrack, watching choreography videos and visualizing her performance. Then rehearsal for three hours.

Preparing for, and performing in, shows can be grueling. Lorton said she keeps Grace to two shows per year at Myers Dinner Theatre. Grace remains insistent that she wants to pursue acting, and mom acquiesces as long as she keeps up her grades. Her enthusiasm for it is written all over her face.

"She tells me the most with her eyes and expressions. It's not necessarily what she says but how she says it," Lorton said.

When he discusses Grace's strengths, Moyer notes her enthusiasm, maturity and ability to become other people. One trait, however, stands out most and feeds into the others.

"She's not afraid to do anything," Moyer said. "Now sometimes she may have to process it a little bit because she's got that analytical mind going, but once she figures out how she's going to do it, she's not afraid to do anything."

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