

Naples Daily News

naplesnews.com | Sunday, August 3, 2014

\$2.00 Sunday

PART 1 OF 3

LITTLE MAN AND THE PURSUIT OF HAPPINESS



Maria Maldonado hugs her son Ethan Arbelo, 11, on the second day of their camping trip to the Redneck Yacht Club on May 25, 2013, in Punta Gorda. Maria decided to take Ethan on the camping trip after he asked for a stripper for his 12th birthday. "Well, I can't get you a stripper, but I can get you as close as possible," she said. "Hence, the Redneck Yacht Club."

Story by Jessica Lipscomb ■ Photography by Dania Maxwell
Printed on page A1

His first kiss happened long after sunset, illuminated by headlights and perfumed by exhaust fumes on a swath of land in Punta Gorda known as the Redneck Yacht Club. Ethan Arbelo had not yet turned 12; the blonde was 26.

The Redneck Yacht Club was a compromise of sorts. There's an adage that if you want a dog, first ask for a pony, and following suit, Ethan, 11, had asked his mother if he could

have a stripper for his birthday.

She thought it over for a while, wondering if she could pull it off without the Department of Children and Families showing up at their Lehigh Acres duplex. It was hard to turn Ethan down, not knowing how many birthdays he had left.

“Well, I can’t get you a stripper,” she told him. “But I can get you as close as possible.”

So this was Ethan’s early present, three months ahead of his August birthday. This was how Maria Maldonado and her son ended up in the back of a swamp buggy on Memorial Day weekend 2013.

As the two rode around the mud park, monster trucks blared a strange mix of Southern rappers and country crooners. Women with dirty feet flashed their breasts for beads. A tumor continued to silently invade Ethan’s brain.

Maria taught her son some basic redneck etiquette: It’s OK to look, but don’t stare. Throw your beads and get on with it.

The two rode with Timmy Mock, a 26-year-old from Lakeland they’d just met who was sympathetic to Ethan’s predicament. He sipped Busch Light from a koozie that read “IT AIN’T GONNA LICK ITSELF” as he carted mother and son around the mud park.

Ethan whipped his beads back and forth as they drove around the property. Before long, a girl on an adjacent buggy motioned for him to throw them over. Ethan pantomimed a lifted shirt, but the girl refused.

She did not earn Ethan’s beads.



He woke early the next morning, same as always, and headed to the food trucks around 8 in search of biscuits and gravy.

As he waited for his breakfast sandwich, he noticed two girls in line, one braless in a lace tank top and the other in an undersized bikini. They learned he had cancer and seemed less creeped-out by his stares.

After breakfast, Maria and Ethan walked to the front of the park for a swamp buggy ride they were promised the day before. A passer-by on a golf cart offered them a ride.

“What’s your name?” the man asked.

“Ethan,” he replied.

“I’m Franklin.”

“I’m fighting cancer,” Ethan said.

Later that night, Maria parked a borrowed golf cart on the parade route and watched Ethan twirl his beads around at pretty women. Word got out that he was terminal.

The girl in the bikini from breakfast recognized Ethan and approached the golf cart. She lifted her shirt, offering her chest as a gesture of goodwill.

As she leaned in to kiss his cheek, he moved his lips to hers and she allowed him a long, wet kiss. It felt, he’d say later, like ice cream melting in his mouth.



Ethan Arbelo, 11, kisses Ashley Schroeder at the Redneck Yacht Club on May 25, 2013, in Punta Gorda, Fla. It was the first time Ethan had kissed a girl. "It felt like ice cream melting on my tongue," he said.



Before he grew gray hairs and began using a wheelchair, before he began sleeping all day and wearing a diaper, Ethan Arbelo was a fifth-grader at Orange River Elementary School in Fort Myers, an 80-pound kid who liked swimming and play-wrestling his mom. She called him her little man.

He was 10, with a reputation as the class clown. He talked tough, but got bullied sometimes because he was too small to back it up. He'd never had a girlfriend but considered himself a ladies' man. He had a full-blown crush on a girl named Victoria Brooks because she was pretty and she wasn't mean.

"That's basically the two main reasons," he said.

He was still a boy, but not in the ways he used to be. He watched "Scooby Doo" but also "Judge Judy," sometimes in the same day. He played with a stuffed panda puppet but called him Dr. Greenthumb, after a weed-cultivating character in a song by the rap group Cypress Hill.

His hero was his mother, who was part Irish, part Puerto Rican and 100 percent spitfire. She looked younger than her 40 years but was as proud of her age as she was of her Marine Corps background and the tattoos and heartbreaks she'd collected over the years.

She sometimes said Ethan, her third and youngest child, was the best thing to come from her failed marriage. She'd divorced his dad, Jose "Tito" Arbelo, in 2004, triggering a custody battle over Ethan and his older sister, Mio, that never seemed to leave anyone happy.

It was one of her scheduled weekends with Ethan in February 2012 when she noticed her son's eyes crossing. She took Ethan to an eye doctor in Fort Myers, who found fluid building up inside his head. They rushed him to the hospital in St. Petersburg, where another doctor found a tumor taking root in his brain.

She remembers looking it up on her phone as soon as they got the diagnosis for anaplastic astrocytoma grade III. About 70 kids were diagnosed with the same disease each year. Most patients made it only two to five years after that.

She told her son the news and even then, right from the beginning, Ethan knew everything was going to change.

They all had their own concept of Future Ethan.

His father imagined him hanging out the window of a slick car, flirting with all the girls.

His mother saw him with lots of kids and a good wife, still the same old clown, still a mama's boy.

Ethan pictured himself as a Marine, a real tough guy, maybe even a drill instructor.

He understood the cancer, because his grandma had it in her lungs. She was dead now. He told himself to keep fighting.

He started making lists of things he wanted to do, things he thought he'd have a lot of time to accomplish but suddenly might not. He wrote a Christmas list asking for a PlayStation 3 and a cancer-free brain.

After another trip to the doctor, he asked his mother if all the treatment was not really to treat him but to give him life for just a little bit longer.

"Yes," she told him, but she added it was to extend his life long enough for scientists to find a cure. It was a lie, of course, but he wasn't a teenager yet, so he still believed her.



Six days after his diagnosis, his parents came to an agreement. Their daughter would continue to live with Tito, who would keep his job as an auto mechanic. Maria, who had been fired at Ethan's bedside from her job as an accountant at a remodeling contractor, would be Ethan's caretaker.

Maria, once a truck driver in the Marines, approached the cancer from a military standpoint. She told Ethan that he was a Marine and that this was his battle and that he needed to fight with everything in his power, no matter how hard it got.

She called herself his commanding officer and said if he listened to her, they'd get through the battle together. She told him Marines aren't allowed to die without permission — and she hadn't said it was OK yet. One day, she would have to suck it up and give him permission to let go. They referred to this directive as "the Order."

There was a time in late May 2012, a little more than two months after the diagnosis, when the doctor said Ethan wouldn't make it more than a few days, maybe a month, tops. That night, his shunt failed and fluid backed up in his brain. He kept yelling out in pain. Maria called in hospice.

She sat on the end of his bed and asked Ethan a question that would come to define everything that followed: Do you want me to help make you comfortable? Or do you want me to help you live?

"And in the middle of everything else," she remembered, "he said, 'I want you to do whatever it takes, Mommy. I want to live.' "



Ethan lived a few more days, then a few more weeks, then six more months. He celebrated his 11th birthday, Halloween, Thanksgiving and Christmas, one after the other, like falling dominoes on the calendar.

He talked a lot about proving the doctor wrong.

“I don’t really care about him. I’m going to do what I’m going to do,” he said.

He hung cancer posters in his room by the ones of superheroes and became an involuntary expert on the language of brain cancers.

“Anaplastic astrocytoma,” he’d say, annoyed. “Pronounce the word, people. It’s not that hard.”



Ethan Arbelo, 11, plays with a radiotherapy mask given to him after completing the last of 28 sessions of radiation at Florida Hospital on May 2, 2013, in Tampa, Fla. Diagnosed in March 2012 with anaplastic astrocytoma grade III, a terminal brain cancer, Ethan was prescribed with merely life-extending, not curative treatment.

If he was worried, he never showed it. He didn’t feel sick.

“They are wrong, trust me. I know they’re wrong,” he said. “At this age, it’s not going to happen to me. The big man’s going to take care of it.”

His mother told him there was no expiration date on the bottom of his foot, that it didn’t matter what the doctors said.

“Those books can say three to five years, doesn’t matter,” she said. “First comes medicine, then comes God.”

When they got bad news, she remembered the time his tumor doubled, how she went home and found a clinical trial that even the doctor hadn’t known about. She remembered how the treatment shrank the tumor by 78 percent and how that bought her son a little

more time.

She counted on miracles like that.



In June 2013, there was another MRI appointment, where they would find out if the radiation had been working. The day started at 5:31 a.m., after several rounds of the snooze button. Maria preferred early-morning appointments so Ethan would have to fast only until noon.

On the way to St. Petersburg, Ethan got out of the car at a rest stop and threw up into a storm drain. He threw up again in the hallway of All Children's Hospital a few minutes before his turn with the radiology team.

An anesthesiologist noticed his new facial hair: "Is that a mustache you're growing there?"

"Yeah," Ethan said. "It's called respect."

The doctors took him away and gave his mom a pager, like one you might get at an Olive Garden. While he was under, she met with a staffer in the lobby about possible clinical trials.

Of the 15 Maria had found online, Ethan was eligible for only three. Two were in New Hampshire and one was in Germany. A blood clot made him ineligible for most others.

During a smoke break, the pager went off. Maria packed up her Newports, stubbed out her cigarette and walked inside.

A nurse gave Ethan some graham crackers, and Dr. Joseph Potthast, a pediatric radiologist, led Maria into a separate room for results.

She'd had a bad feeling all morning, an instinct that the tumor was progressing. But in the hallway, the doctor's words surprised her.

"We have pretty good news," he said. One of Ethan's tumors had shrunk by roughly an inch, and everything else appeared stable.

Back in the car on the way home, Maria broke the news.

"You're winning, Ethan," she said, and the two fist-bumped above her headrest.

Maria pointed the car south on Interstate 275. Around mile marker 20, she started to cry.



He was confident he'd beat it.

"When I started off, mine was a stage III, so I've been fighting. I'm pretty sure it's stage II," he said that summer.

With the help of his mom, he started making a bucket list, just in case.

He wanted to shoot a gun, to lose his virginity, to get President Barack Obama out of the White House, to go sky diving.

He and his mom made a mental checklist of his wishes, which ended in a plan for a cross-country road trip. He wanted to see the Grand Canyon, visit his grandfather in New Mexico and put his hands and feet in four states at the Four Corners. Maria set up a fundraiser page on GiveForward and asked for help to make it happen.

Sixty-five donors pitched in more than \$5,600. They left June 15 for their first stop in Alabama.

It had been a year since Ethan left school, and exactly zero of his classmates had kept in touch. In Tampa, they picked up Lea Sellwood, a 9-year-old from the cancer circuit who

Naples Daily News

naplesnews.com | Monday, August 4, 2014

\$1.00 Daily

LITTLE MAN AND THE PURSUIT OF HAPPINESS

PART 2 OF 3



Ethan Arbelo, Maria Maldonado and Lea Sellwood, left to right, look out onto the desert at a meteor impact site on June 25, 2013, just outside of Winslow, Arizona. They had set out the week before on a cross-country road trip, with a bucket list for Ethan to experience the things he wanted. "The crater was pretty cool," Ethan said.

Story by Jessica Lipscomb ■ Photography by Dania Maxwell
Printed on page A1

Midway through his French toast in June 2013, Ethan Arbelo hurried to the bathroom and shut the door.

Soon after, his mother heard him faintly calling for her. She got up from the table and went into the bathroom, where a spray of blood covered the toilet.

"Where's the closest emergency room?" she shouted. Ethan, who had finished vomiting,

held a tissue to his face to stop his nosebleed. They were in California, 2,600 miles from their home in Lehigh Acres.

A friend called 911 and minutes later, paramedics parked their engine outside and headed over to investigate.

“This is Ethan, he’s 11,” one of them said, briefing a colleague. “He’s got, uh, it’s basically brain cancer.”

“It’s called anaplastic astrocytoma,” Ethan said.

The paramedics loaded mother and son into the ambulance and headed to the Tri-City Medical Center. In the emergency room, a nurse began to fill out paperwork.

“Where are you visiting from?” she asked.

“Florida,” said Maria, 41. “He’s on his bucket list.”

Another nurse warned Ethan about a needle, but he shrugged her off.

“That’s the difference between me and most kids. Most kids are like noooo noooo,” he said.

Maria called Ethan’s doctor back in St. Petersburg to make her aware. The emergency room doctor cleared Ethan to go home, but he insisted on heading to the beach first.

Peeling his shirt off, he ran out onto the sand and into the cool Pacific water. Ethan and two other kids took turns burying each other in the sand.

His mom stood up the beach watching, taking in the salty California air.

“You’d never know that two hours ago he was bleeding,” she said.



After his diagnosis in 2012, Ethan started making a list of things he wanted to do and memories he wanted to make. He was certain he wasn’t actually dying, but figured it didn’t hurt to check off a few items either way.

With his help, his mother pulled together an itinerary for a cross-country road trip so Ethan could see faraway places. They left their home in June 2013, picking up his friend Lea Sellwood, a 9-year-old with leukemia they knew from All Children’s Hospital in St. Petersburg.

In Alabama, they met up with one of Maria’s friends from her Marine Corps days, visited a waterfall near an Army base and sang “Ice Ice Baby” on the way to a ghost-hunting excursion. Next was New Orleans, where they ate po’boys on Bourbon Street, and Houston, where they went on a local radio program to talk about the need for funding for pediatric cancer.

After a quick visit with Ethan’s Uncle Bubba in Lubbock, Texas, they made their way to New Mexico to surprise Ethan’s grandfather.

Jose Maldonado greeted his surprise visitors shirtless, dressed in a pair of black shorts and shearling house slippers. The 74-year-old invited them inside and began flipping through the channels as Maria pulled out old photo albums.

“You don’t know when you’re going to die,” Jose said eventually. “People say you’re going to die, then you don’t, you know?”

The next day, as they kissed goodbye, Maria began to cry.



Ethan says goodbye to his grandfather, Jose Maldonado, after his mom, Maria Maldonado, right, surprised him with a visit June 24, 2013 in Tucumcari, N.M.

“I’ll be back soon. I won’t wait five years next time,” she said.

“I might not be here next time. But if I’m going to die, I’ll call you. ‘Maria, I’m dead!’ you know,” her father joked.

He turned to his grandson.

“I’ll see you later. Try not to think about nothing, OK?” he said. “Life is about nothing but the choices you make.”

■ ■ ■

Stopped for the night in Holbrook, Arizona, Maria gave Ethan some anxiety medicine to help him sleep. Dinner was late, around 9 p.m., at a Denny’s across the motel parking lot.

Ethan ordered a Junior Grand Slam, then sunk into the vinyl booth for a nap. His mom put down her silverware and started crying. She hated to see him sedated.

“Are you OK?” the waitress asked.

“He has cancer,” Maria said. “He’s tuckered out. We’re on his bucket list.”

She got the check and took Ethan back to the motel. Maria and Lea got on either side of him and helped him up the stairs and into bed.

Outside, Maria puffed on a Newport and choked back tears.

“I hate it because I feel like that’s not my son,” she said. “And I really want to finish the bucket list, because I don’t want it to be undone. I don’t want to get home and find out that something else is wrong and he hasn’t finished it.

"I don't want to push him too hard and it's just, the money's running out, and it's just like ... it's just a lot," she said.

She finished the cigarette.

"I'm determined to do it. I'm just going to finish my updates and go get some sleep," she said, slipping back into Room 239.

She titled her blog post "Today's hard decision" and began to write: "It was a really rough day today."

■ ■ ■

In the car the next day, Ethan asked to call his dad.

"Always have faith. Faith will move a mountain," Tito Arbelo told his son.

"I love you," Ethan said. "I miss you."

They took a pit stop at the Meteor Crater, about 40 miles east of Flagstaff, Arizona. After purchasing tickets, they walked the edge of the mile-wide crater listening to tour guide Derek spew off facts about the crater's age (50,000 years old) and size (2.4 miles in circumference).

"This is a beautiful view, ain't it?" Ethan said. "B-E-A-U-tiful."

Before they left, Maria asked if he wanted to go up to the observation deck.

"I'm not going up there," he said. "My pits are moist."

■ ■ ■

After three weeks on the road, with stops in New Mexico, Oklahoma and Arkansas on the way back from California, they pulled into their driveway in Lehigh Acres on July 5.

At the hospital for a post road trip checkup later that month, the nurse weighed Ethan at 127 pounds, about 12 pounds heavier than the last visit.

"Mommy put on some too," Maria joked.

"It's not a good vacation if you don't," the nurse said.

Soon after, Ethan's pediatric oncologist, Dr. Stacie Stapleton, came in to see him. By now, he knew the sound of her heels clicking down the hallway and could tell when she was approaching.

They discussed new combinations of chemotherapy Ethan might try. Maybe CCNU and temozolomide?

"There were several patients that were on that that had fairly decent results," the doctor said.

"All right, so what do you think? Take some oral chemo by mouth?" Maria asked Ethan.

He said nothing.

"You need it, baby," she coaxed.

"I'll do it," he said quietly.

■ ■ ■



Maria puts on Ethan's shoes as he looks at his homecoming date, Lydianna Mize, on Oct. 12, 2013, in St. Petersburg. The dance was hosted by All Children's Hospital for pediatric patients. "I'm nervous for Ethan," Maria said. "This might be his first and last homecoming."

Later that fall, Ethan picked out a black tuxedo with pink accents for his first homecoming dance. He asked Lydianna Mize, the 10-year-old sister of his friend Morgan, another cancer kid, to be his date.

The dance, held on a Saturday in mid-October, was the first of its kind at All Children's Hospital, an event dubbed "Evening Under the Stars" for pediatric patients. Almost everything was donated: Chick-fil-A sandwiches, ballgowns, a twinkly carriage parked outside to take pictures with.

Ethan and his date walked underneath an arch of balloons into the dance room. A girl in a wheelchair wore a tiara atop a hairless head. Another kid sported a gorilla mask. The room smelled overwhelmingly of cookies.

The kids did the "Cupid Shuffle" and the "Wobble" and obliged when asked to film a "Harlem Shake" video. In between dances, Ethan sat on the stage. An older teenager in a pinstriped suit said hi.

"He has what I have," Ethan said. "Brain cancer."

Around 10 p.m., Ethan and his date met his mom in the lobby. One of the other moms told Ethan he looked handsome.

"We gotta go home," Maria told her, "so he can take his chemo."

■ ■ ■

Their duplex was sparsely decorated — not really the priority — but family photos were given prominent wall space. Hung on the kitchen wall as soon as you walked into their duplex was a boot camp portrait of a young Maria in Marine Corps dress blues. To the right of her photo was the same type of portrait of her brother.

She called it the “Wall of Fame.” Every good Marine had one. Ethan thought he might end up on the wall one day, too.

“I want to be a Marine,” he said. “If I become a Marine, then instead of retiring I want to become a drill instructor, always yelling at people.”

When Ethan was diagnosed, Maria assumed that role.

“She treats me like she’s my drill instructor and I’m her recruit,” he said. Marines weren’t allowed to die without permission, without “the order.”

That fall, she finalized plans to make him an honorary Marine, an honor bestowed to fewer than 100 people since it became a formal title in 1992. She called her plan Operation Devil Pup, a spin on the “devil dog” nickname for Marines.



On Halloween morning, Maria drove her son to the 4th Assault Amphibian Battalion Headquarters in Tampa, just outside the Marine Central Command at Air Force Base MacDill.

Ethan, at first a little confused, realized he was the guest of honor.

“Making you an honorary Marine,” said Lt. Gen. Robert B. Neller, the highest-ranking official on base, “is our way of recognizing that you’re resilient, you’re faithful, you never quit. You find a way to overcome.”

The ceremony was short. Someone asked Ethan if he wanted to shoot a grenade launcher, which seemed more fun anyway.

He turned his attention to an amphibious assault vehicle.

“Will I get to drive it?” Ethan asked. “I really want to drive it.”

They plopped a helmet onto his head, helped him into the back of the vehicle and took him for a spin.

“See? Now you’re a real Marine. You sweated with ‘em,” his mom said.

The ceremony was for him but it was also for her. Maria remembered walking across the parade deck for her own graduation, and how everything she had been through — her entire crappy childhood, her years in high school — how at that moment, everything was somehow finally worth it.

“When you walk across that parade deck and you do eyes right, and you see the person that means the most to you looking back and the pride in their face, you’re just like, yeah,” she said later. “And I wanted that for my children.

“The only one that really had the balls enough to do it was Ethan. And I feel robbed. Even with him having honorary Marine status, I feel robbed. ‘Cause I want to know what my dad felt. And I only got to feel a portion of that.”



Ethan plays with the headgear while riding in an assault vehicle after being made an honorary Marine "Becoming a Marine, makes you feel legendary," Ethan said.

■ ■ ■

The next month, at the end of November, Ethan was due for another MRI. Maria knew his tumors must be doing work because of the palsy, the way he couldn't quite move his left hand like he wanted to.

It took only a few hours to get the news from Dr. Joseph Potthast, a pediatric radiologist. The tumors were growing, now taking over his spine.

After lunch, they met with Ethan's oncologist.

"What do think about doing chemo?" Dr. Stapleton asked.

"I say let's give it a try," Ethan said.

"OK," she said. "What if it makes you feel bad?"

"Keep going," he said. The doctor asked Maria if they could speak privately.

"Only God knows," Dr. Stapleton said. "But I would say with that amount of progression ... you know, his poor little brain. It's almost more tumor than brain, at this point."

"How do you tell a Marine to stop fighting?" Maria asked.

"You have done everything," Dr. Stapleton said. "You have done your homework, you have done your research, you have reached out across the country to me, you've brought me papers, you've emailed me ... you have done, you have done everything. You couldn't have possibly done any more as far as trying to find a way to cure him. The problem is — it's we, as a medical community, don't have the ability to cure this tumor."

They talked for a while and decided it was time to approach Ethan.

The two walked into the room where Ethan sat, reading from a book of jokes called "Monkey Farts."

"Dr. Stapleton said it's time to issue the order," his mother said.

"No. It's not," Ethan said.

"She said the chemo won't help ..."

"It's not time yet."

"... that it's growing too fast."

"It's not time."

"I am afraid," she said, crying.

"Don't cry," he said. "Dr. Stapleton isn't my commanding officer. You are."

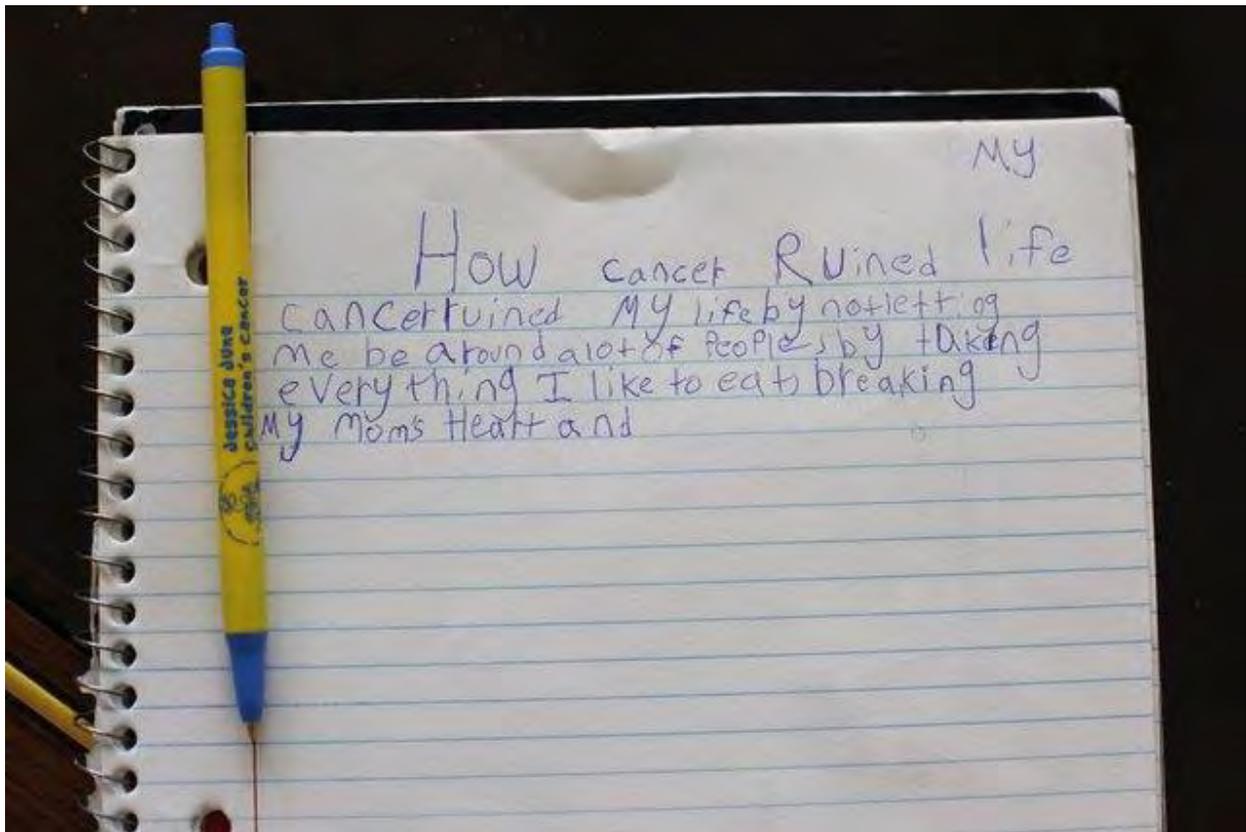
"She's God's messenger," Maria said.

"God makes miracles," he insisted.

He talked to his dad on the phone on the way back, said he was feeling good.

"It'd be nice if you came to see me though," he said. "Cause I got Battlefield 4 ... OK ... All right ... Love you, too."

They made it back to Lehigh around 7:45 p.m. Ethan said his prayers and went to sleep.



As Ethan Arbelo starts to accept the prognosis of his disease he writes a note in his journal before bedtime on July 30, 2013, in Lehigh Acres, Fla. He was on the fifth and final day of a pill form of chemotherapy that made him sleepy. His mother said he probably fell asleep before finishing his thoughts.

Naples Daily News

naplesnews.com | Tuesday, August 5, 2014

\$1.00 Daily

LITTLE MAN

PART 3 OF 3

AND THE PURSUIT OF HAPPINESS



Too weak to walk, Ethan Arbelo plays with Superman action figures in January in a reclining chair where he spends most of his days at his home in Lehigh Acres. "It's heartbreaking watching your child revert," his mother, Maria Maldonado, said.

Story by Jessica Lipscomb ■ Photography by Dania Maxwell
Printed on page A1

On a November morning last year, Ethan Arbelo snuggled up to his mom on the couch and pointed to a picture of his brain on her laptop screen.

"That's what my head looks like now?" he asked.

Maria Maldonado nodded. He pulled up her Facebook page and commented on the photo.

screw cancer im stronger

Ethan, 12, lounged unaffected in camouflaged PJs, sipping chocolate milk from a Marines mug. He finished, then headed to his bedroom to fight a war on his Xbox.

Before they left Lehigh Acres for an appointment with his radiologist, Maria took her son in the hallway and told him the chemotherapy might not work this time.

"I want to fight with it until it's dead," Ethan said. "I don't want this tumor to win."

"This is your Hail Mary, like in football," she said. "It's the last thing you can do to get in the end zone."

"It's OK," Ethan said. "I know it's going to work. God makes miracles, doesn't he?"

"Yes he does," she said. "We'll figure it out, OK?"

"I'm not going to die," he said softly.

■ ■ ■

The dual forces of medicine and puberty were manifest on Ethan's upper lip. He was proud of his mustache and the respect he perceived it commanded, but his so-called commanding officer still wanted him to look like a kid. After their grown-up conversation, she brought him into the bathroom for a shave.

Ethan sat on the toilet while Maria moved the razor across his face and behind his neck, careful not to nick him.

"Sit like a good Marine 'til I'm done shaving, OK?" she said.

When she was through, he stood up, noticing he was almost as tall as she was.

"So sexy," he said, looking into the mirror.

"Right?" his mom said. She fluffed up his hair and sprayed him with some Samba cologne he'd swiped from his dad's house.

"This smells kind of papi chulo-ish," his mom said.

Ethan expected his dad to stop by, but hours ticked by without his arrival.

"I think he lied," Ethan said.

Before leaving for the doctor, he grabbed an apple from the kitchen.

"You know what they say," he said. "An apple a day keeps the you-know-what away."

■ ■ ■

There were certain things they got to know once they were inducted into the world of pediatric cancers. It was a club no one wanted to be a part of.

Maria knew it was 126 miles each way to All Children's Hospital in St. Petersburg. Ethan knew how to pronounce the technical name of his brain tumors, anaplastic astrocytoma. He knew when he made a friend at the hospital that he was hitching his heart to someone who might not be around when it was time for his next appointment.

Maria connected with a group of cancer moms at the hospital. They added each other on Facebook, shared each other's posts and swapped advice about chemotherapies and clinical trials from their own experience. When she needed them, they offered an understanding ear, an outlet to vent or a couch to crash on.

Maria and Ethan were on the way to the hospital in early December when she got word that one of the cancer mom's sons, a 3-year-old, was "transitioning," as they called it.

"What's happening to Morgan?" Ethan asked when she got off the phone.

“He’s dying, baby. It’s his day,” Maria said. “Lakeysha just called. It’s time for him to get his wings.”

“That sucks,” Ethan said quietly. “I can’t believe Morgan is dying.”

He started crying a little. “I just get stressed out losing a friend.”

“Shit just got real, huh?” his mom said.

“If I have to fight for 10 years to get rid of it, that’s fine by me,” Ethan said.

She promised they’d visit Morgan after their appointment. They continued north to St. Petersburg. The radio stayed tuned to a Christmas station:

It’s the most wonderful time of the year

It’s the hap- happiest season of all

■ ■ ■

At the hospital, one of Ethan’s doctors, a soft-spoken blonde named Stacie Stapleton, came in and took a seat next to him.

“This is the deal with us continuing to fight as we always have,” she said. “This tumor is — it’s a big bad tumor and I’m scared that we’re not going to win, that the tumor’s going to win. And I’m willing to fight it as long as you want to and your mom tells me whatever you want to do.”

“I want to fight with it until it’s dead,” Ethan said. “I don’t want this tumor to win.”



Maria gives Ethan a hug after giving him “the order” to die with her permission on Nov. 20, 2013, in St. Petersburg. When Ethan was diagnosed, Maria assumed the role of a drill instructor and Ethan was her recruit. Maria told Ethan when the time came, she would tell him. “I’m not going to die,” Ethan said.

“We all die,” the doctor said. “And making it a, um, a peaceful process where everyone respects your body and, um, is gentle with you and not like it’s on TV and they’re doing stuff to you — I just want you to think about that. If the tumor wins, would you want to die naturally or do you want, um, it to be a sort of a chaotic, um, stressful process?”

“Normal. I’d rather die and just kind of ...” Ethan said, his voice trailing off. “Like, what is death?”

“Well, um, that’s a big philosophical question that I don’t, I don’t know. I just know we can’t walk and talk and feel our heart beats. I don’t know what it is, if there’s some sort of transition to another place, another state,” Stapleton said.

Ethan asked if he could do chemotherapy and radiation at the same time.

“If I have to fight for 10 years to get rid of it, that’s fine by me,” he said.

“If it’s going to hurt you worse than it is now, I don’t want you to do it,” Maria said.

“Cause right now, you can still laugh, you can still play, you can sit on the bed and play your video games with your buddies. What if you’re not able to do that if you take the chemo? What if it makes things worse?”

“I don’t want you to be scared, OK?” Maria told Ethan.

“That’s fine,” he said.

“It’s not OK,” Maria said. “Quality, not quantity. Do you know what that means? It means it doesn’t matter how long you live your life, it’s how you live your life that counts. Do you want to make memories or do you just want to make time?”

“Make memories,” Ethan said.

“So maybe, we’ve talked about this, maybe that’s the way to go,” she told him.

■ ■ ■

After leaving the hospital, they began the short drive to Morgan’s house.

“I don’t want you to be scared, OK?” Maria told Ethan.

Back in the master bedroom, Lakeysha Mize lay with her son Morgan, who had dwindled to 27 pounds. His eyes were closed and an oxygen tube was strung between his ears. Maria stroked his thin blond hair.

“Don’t be afraid,” she said quietly. “You’ll be with Ethan soon.”

She went out to the kitchen to see if Ethan wanted to say anything. They walked back into the bedroom together.

“Hi Morgan, it’s Ethan. Remember me?” he said.

There was no response.

“He’s sleeping,” Ethan said.

They said goodbye later that night, then drove home to Lehigh Acres. Morgan died two days later, less than two weeks before his fourth birthday.

■ ■ ■

After their hospital visit, Maria updated her Facebook page with a post about the doctors saying there was nothing more they could do for Ethan. A woman left a comment inviting her to learn more about medical marijuana.

It wasn’t legal in Florida, but even the National Cancer Institute acknowledged that cannabinoids had the potential to kill cancer cells and reduce the growth of tumors.

After being connected to the right people, Maria was assured a package would make it to their doorstep just before Christmas.

On Dec. 10, a man from a local funeral home came to their home to make final arrangements.

“The reason he’s here,” Maria told Ethan, “is because — you remember I told you this morning, we’re getting that package? But there’s no guarantee it will work. And if it doesn’t work, you know what’s going to happen. What’s going to happen?”

“The D word,” Ethan said.

“The D word, that’s right,” his mom said. “Want to say it?”

“D-E-A-T-H. Death,” he said.

“Don’t be depressed, OK?” she said.

The package arrived later that month, and she began administering the cannabis paste, pills and candy. She worried that it wouldn’t work or that it was too late, but not as much as she worried Ethan would die while there were unused, if not alternative, weapons in her arsenal.



Ethan spent Christmas Eve at his dad’s place, which was actually his grandparents’ house, about 20 minutes away from his mom’s home.

Nearly all the relatives on his father’s side were spread throughout the home, drinking on the porch, chatting on the couch, helping out in the kitchen.

As midnight drew closer, they met in the living room to start swapping gifts.

“You want to come open your presents?” Ethan’s grandmother said.

With a limp hand, he lifted the green paper off a Superman action figure, then a Nike shirt, then a Nerf gun.

He thanked his dad and his grandparents for the presents then went off to bed.

After his diagnosis, Ethan saw his grandparents regularly, but his father stopped by infrequently.

Tito Arbelo remembered walking straight to the elevator at the hospital when his son was diagnosed. He left the building and just kept walking, in no particular direction, for miles at a time, until he was lost.

“I was completely destroyed,” he said. “I haven’t been my person since then.”

It angered him when people called him a deadbeat dad — after the divorce, Tito had primary custody while Maria worked a job in Winter Haven. She’d assumed full custody of Ethan immediately after his diagnosis. He begrudged those who didn’t acknowledge his early years with Ethan.

“It’s like they don’t know that part,” he said. “They think I’ve been absent.”

“I think your daddy loves you,” Maria said. “He just can’t see through his hurt.”

He admitted he didn’t have the best relationship with his son, said they didn’t understand each other.

“I loved him, but I was always very strict,” Tito said.

He gave a lot of reasons for fading from the picture since the diagnosis: He wanted to make sure Ethan’s sister, Mio, got enough attention. It was hard to take time off from work. He didn’t know how to talk to Ethan about death. He didn’t want his son to see him cry.

“I think it was better for him that I not be at the hospital sometimes,” he said.



Jose "Tito" Arbelo decompresses on January 17, 2014, after an argument with his ex-wife Maria Maldonado about his absence in their son, Ethan Arbelo's life after he was diagnosed with cancer, in Lehigh Acres, Fla. A third grade school portrait of Ethan from two years before his diagnosis hangs on the wall beside him.

Ethan wasn't convinced. In the beginning, he was mad when his dad didn't show up, but as the time since his diagnosis passed, he had grown to expect it. Maria told him that sometimes daddies weren't as strong as mommies.

"I think your daddy loves you," she said. "He just can't see through his hurt."



At the beginning of the new year, an 18-year-old named Reggie Iacono moved into the spare room of Ethan and Maria's three-bedroom duplex.

His mother, an old friend of Maria's, had pleaded with her to let him stay for a couple of months. Reggie's girlfriend was expecting their first child, and he was crashing with friends without a permanent home. They worked out a trade: Reggie would help with Ethan, and Maria would take care of the rent and food.

Since August, Maria had been working as an accountant for the property management company that owned their duplex, leaving Ethan with his grandparents and working from home when that wasn't an option. Her boss understood Ethan's constant but manageable needs, and it was the longest job she'd held since Ethan had been diagnosed.

In that regard, Reggie's arrival was well-timed. He was a caretaker, but he was more than that. One day at the hospital, after wiping the residue from a bag of SunChips from Ethan's hands, a nurse asked about their relationship.

“We’re more like brothers,” Ethan told her.

By the time February rolled around, Ethan was spending most of his time at home, with occasional trips to a friend’s pool or to stay with his dad, who was starting to be more available. When Reggie asked to borrow the car to take Ethan out on the town a few times, Maria slipped him a \$100 and told them to enjoy a boys’ day.

On Feb. 21, after a haircut at G O’s Barbershop, Reggie pushed Ethan’s wheelchair across the parking lot of Hooter’s and onto the outside deck. The two dressed in stripes, Reggie in a tank top in shades of gray and Ethan in a navy and white striped T-shirt. Ethan’s favorite waitress, a waiflike brunette named Andrea Salazar, was working, and he greeted her with a quick kiss on the cheek.

After lunch — two orders of wings and curly fries — Reggie and Ethan popped into the Edison Mall.

They headed first to Lids, where Ethan picked out a red Oklahoma City Thunder flat bill hat, and then to Spencer’s, where he chose a poster of Maxim’s “hometown hotties,” a row of toned bikini models wearing red, white and blue bikinis with their backsides facing the camera.

Walking past the shops, Ethan tossed a coin in a mall fountain, where he made a wish he never revealed. He asked to go into the Disney store, where he picked out a stuffed animal of Sulley from “Monsters Inc.” and gave it a squeeze.

Reggie humored him for a few minutes before gently suggesting maybe it was time to shop somewhere more adult. They left without making a purchase.



“I beat my cancer,” Ethan said in late March, more than two years after his diagnosis. He was having trouble walking, so he sat in his favorite brown recliner watching “Transformers.” A pair of Marine Corps dress blues — the outfit he would wear to his funeral — hung on the door of his mother’s closet at the back of the house.

“You did?” she asked him.

“Uh huh,” he said.

The night before, Maria had noticed signs in his eyes from the hydrocephalus, the swelling on his brain, but today, she saw him looking like himself for the first time.

“I look like a man,” he said from the recliner.

“You’re incredible, baby,” she told him.

She secured a bib around his neck and gave him a dinner of sausage pizza and Pepsi in a sippy cup.

“I want a wife,” he said later that night.

“What do you want a wife for?” she asked.

“So I can grow up and have kids,” Ethan said.



His preteen body was already changing so much, but cancer had its own way of leaving its mark. In April, Ethan had resumed steroid treatment, his skin growing and stretching to accommodate the weight gain. Thick red stretch marks spun webs across his body at the same time he began sprouting more body hair and developing the skin of a teenager.

“Is that a pimple?” Reggie asked him one day, pointing at his chin.

He had less privacy than the average boy his age but all the same urges, on one occasion finding himself in the classic teenage predicament of being caught by mom.

His outer body didn't match his inner self. He still thought he was sexy, but he was embarrassed by his growing body. He wanted more than ever to lose his virginity, but it didn't seem likely while he was wearing a diaper.

Maria was home all the time now, having quit her job after about six months to accommodate Ethan's increasing needs. His teacher, a woman named Bobbie Henderson who taught homebound children in Lee County, continued to stop by as she had for two years, but Ethan was finding it hard to focus on his lessons.

One night about a week before Easter, Ethan's parents carried him to the bathroom, encouraging him to try to hold his own weight, which had grown to about 180 pounds.

"C'mon, c'mon," Maria said.

"Little steps," Tito guided.

A few days earlier, hospice had moved Ethan's hospital bed into the living room, where he could watch the big TV and have a view of the front yard. The doctor said it was most likely the beginning of the end.

"It's like becoming a child again, becoming a baby again," Tito said.

■ ■ ■

Later that month, Ethan arrived at the Hooters in Naples in the back seat of his mother's car. Before leaving, she packed him an extra T-shirt and a set of baby wipes in case he had an accident.

Hooters waitresses from across South Florida were competing in a swimsuit competition, and a group of local Marines had been asked to judge. Sgt. Joel Slaymaker, a Marine recruiter who met Ethan in December and had since grown close to the family, had invited Ethan to be a guest judge.

The area in front of the stage in the parking lot was blocked off, and a group of Marines carried Ethan and his wheelchair over the barrier so he could sit beside them at the judges' table. Maria ordered him a plate of barbecue wings and curly fries and cut the food into pieces.

Jason Derulo's "Talk Dirty" blared through the speakers as the women tugged at their bikinis behind stage. An emcee began introducing the contestants.

"No. 2, in fierce animal print, we have Haley from Fort Myers" ... "Her favorite foods include corn dogs and sushi" ... "She wants to travel the world and own her own farm."

Slaymaker helped Ethan write down his notes: No. 5, "great spirit," No. 11, "bang bang." Before they left, the contestants circled Ethan's wheelchair so his mom could take a photo.

To his right was a waitress with smooth, caramel-colored skin and a green bikini that matched her eyes. As the camera flashed, he reached up toward her chest and copped a feel. In the photos that followed, the girls are seen with open mouths and wide smiles, their jaws dropped.

Ethan, slumped in his wheelchair, is smirking.

■ ■ ■

Just before his bedtime in early May, Maria caught Ethan scratching the stretch marks on his stomach.

“Give it some fight, for fuck’s sake,” she yelled. “Stand up. I’m tired of telling you not to do that.”

She smacked his hand, the slapping of skin making an audible thwack.

Maria knew about caregiver syndrome — knew about the burnout and the resentment and the anger someone like her was bound to feel — but she wasn’t immune to it.

“I love you, but I want some fight back in you,” she said.

She looked down at her hands, remembering the cocktail ring she wore on the hand she hit with.

“Now I feel like an asshole,” she said.

She apologized to Ethan, who had grown quiet.

“Sorry, my ring got you,” she said, kissing him. “But I bet you won’t scratch now.”

Even months later, she wished she could take it back.

■ ■ ■

By June, Ethan was saying very little. He stayed in bed, watching TV or occasionally playing on a tablet.

“He’s just eating and sleeping now,” Maria said.



Maria Maldonado prepares Ethan Arbelo, 12, for sleep on May 21, 2014, in Lehigh Acres, Fla. Ethan was losing his eyesight due to the buildup of fluid inside his brain. "It feels like I'm losing my best friend," Maria said.

His closest companion, besides his mother, was a tiny black cat she'd given him a few weeks back. He called the kitten Noah, the name he thought he'd someday choose for his son.

While Ethan was eating pizza one night, Noah jumped onto his hospital bed and sat on top of Ethan's head.

"I'm his father," Ethan said, breathing heavily and then starting to doze off.

To pass the time, Maria started reading to him from "The Fault In Our Stars," a best-selling novel about two teenage cancer patients who fall in love.

"The thing about dead people," Maria said, reading from the book, "the thing is that you sound like a bastard if you don't romanticize them, but the truth is complicated, I guess. Like, you are familiar with the trope of the stoic and determined cancer victim who heroically fights her cancer with inhuman strength and never complains or stops smiling even at the very end, etcetera?"

"Indeed," another character was saying. "They are kindhearted and generous souls whose every breath is an inspiration to us all. They're so strong! We admire them so!"

Even if Ethan wasn't paying attention, his mom got a kick out of that part.



Using the remote to adjust Ethan's bed upward on another day in late June, Maria began speaking in the voice of a chipper flight attendant.

"Please keep all hands and legs inside the vehicle at all times. Keep your seat belt on until the captain has turned off the seat belt light," she said.

"Baby, are you in pain anywhere?" she asked.

"No," he said.

"You sure?"

"Yeah," he said.

A group of bikers called the Lost Riders stopped by that night to visit. Since learning of Ethan's illness, they'd helped fundraise for the family and continued to drop by the house every so often to check up on him.

They had names like Wrench and Pop Rock and Boner. They made Ethan an honorary member — the youngest ever — and called him E-Man. Ethan could tell they were coming by the rumbling of their bikes down the road.

Standing at his bedside, they tried to engage him in conversation.

"What's on your mind?" one woman said. "Can you tell me something? Anything?"

Ethan just looked at her, an oxygen tube resting on his upper lip. A catheter bag hung from the side of his bed.

"He can't talk a lot, but he can listen," Maria would tell visitors. "He doesn't laugh real loud, but he still laughs. He knows what's going on around him."



On July 1, his vital signs were still good, but hospice had started giving him morphine.

Maria, who relied on Medicaid to finance Ethan's care, sat on the couch making a call to the staffing agency to request a nurse for the day shift. A nurse had been helping Ethan for about a month from 7 p.m. to 7 a.m., but there was no one to help Maria during the daytime hours.

“Well, I’d like to have it before he’s dead,” she said to the woman on the phone. “I hate to be an asshole about it, but that’s where I’m at. I don’t think they understand the urgency of what’s going on.”

The woman on the phone talked to a manager, who eventually relented. Maria began to adjust Ethan to change his diaper.

“Second-floor, women’s lingerie,” she joked, using the remote to crank his bed to a higher position.

“Hello, gorgeous,” she said, looking into Ethan’s face. “I know you’re in there.”

The phone rang later, a friend calling to check on Ethan.

“Days,” Maria said. “At the rate he’s going, days. He’s not going to bounce back from this.”

She believed the cannabis had given Ethan an extra six months, but she could tell it wouldn’t be much longer.

A ragtag group of friends began to arrive at the house — Denise Simmons, whose teenage son had recently died of a brain tumor; John “Pop Rock” Brubaker, Tony “Wrench” Terranova and his wife, Chris “Mama Bear” Terranova, members of the Lost Riders; Jeanne Nadeau, an Air Force veteran and member of the Patriot Guard; Moriah Barnhart, a Tampa woman whose 3-year-old daughter has brain cancer; and Tonya Stubbs, an old friend of Maria’s who called her a sister.

“I know you’re ready in there,” Maria Maldonado said softly. “You gotta go home. Let your body do its thing. You gotta go home, baby.”

As the nighttime nurse neared the end of a shift on the morning of July 3, a new nurse arrived, a 21-year-old named Eloy Otero. He had been on the job for only two months. He had never watched anyone die.

“It might happen on your shift,” Maria told him. “So if you don’t panic, I won’t panic.”

■ ■ ■

That day inside the house, it felt as if nothing else were happening in the entire world. Friends and visitors came in and out, speaking in hushed tones. Maria constantly checked Ethan’s oxygen levels. She began playing some of his favorite songs — “All My Exes Live in Texas,” “Brown-Eyed Girl,” “Seven Nation Army” — and curled up next to him in the bed.

“I know you’re ready in there,” she said softly. “You gotta go home. Let your body do its thing. You gotta go home, baby.”

The nurses used a machine to suck the fluid out of his lungs. Maria got up to put on “The Heat,” one of his favorite movies. Ethan kept making a sound like a wet snore.

His father arrived later that day, knocking at the front door. His ex-wife met him outside, the two erupting into another argument.

“You should have been here three days ago!” she yelled. “Come on! You want to see him or not?”

Tito got back in his car and pulled out of the driveway. He came back a few minutes later, when he’d calmed down, and told Ethan he loved him. He stayed a few minutes, then left again.

■ ■ ■



Maria Maldonado cries while hugging Ethan as he transitions into death on July 3 at his home in Lehigh Acres. She barely left his side since the day before. "In those last minutes when you know your son is taking those last breaths, all you're doing is praying for death for you, too, because you can't imagine life without your baby," she said.

Just after 6 p.m., the nurses measured Ethan's respiration rate at 5 percent. They couldn't find a heartbeat.

Ethan's hand fell limp over his mother's body, turning purple. A friend ran outside of the home crying.

"Baby?" Maria said. "Baby?"

The hospice nurse called the time of death at 6:31 p.m., and Maria screamed.

The crowd moved outdoors, lowering an American flag outside the home to half-mast. Inside, Maria could be heard yelling for God.

Ethan's father's family began arriving, and Tito went inside to say goodbye. He told Ethan he was proud of his fight, said he was sorry he didn't get along well with his mother.

When Tito was finished, he started telling another visitor that he had the "true story" of Ethan's journey, and Maria yelled at him to leave. He hopped into a pickup across the street, his voice piercing the quiet as he yelled obscenities out the window.

Inside, Maria stayed next to Ethan's body, wishing she could join him in death.

"I love you," she said, touching him. "I love you so much."

As the van from the funeral home pulled away with Ethan's body about an hour later, Maria turned to her other children outside the home.

"You will live your life for him," she told Ethan's older brother, Jose. "You only get one shot, you hear me?"

Firecrackers went off in the distance.

“Get as far away as you can for college and make it, OK?” she told Ethan’s older sister, Mio. “I love you.”

She sat on the porch that night talking with her friend Moriah, whose 3-year-old daughter has brain cancer.

“Mourn the loss of your child; don’t mourn the loss of your child’s life,” Maria told her. “My child fucking squeezed in a grownup’s life. You only have so much time to squeeze out.”

■ ■ ■

On a Saturday a week later, Maria awoke after three hours of sleep and sat in the bathroom, where a cousin began curling her hair.

“I feel weird today,” she said.

The plan was for the Lost Riders to pick her up around 10:30 to head to the funeral home, then the church, then a pool hall called Diamonds Billiards in Cape Coral for a modified Irish wake. Eleven months earlier, the same bar had hosted Ethan’s 12th birthday.



As "Amazing Grace" is played by a bagpipe player, Maria Maldonado lifts her glass in celebration of Ethan Arbelo's life with friends Chris Terranova, left, and Joanne Debono, right, on July 12, 2014, at Diamond Billiards in Cape Coral, Fla.

“The enormity of everything hit me yesterday,” Maria said. “Especially with the wake. The same place we celebrated his life, we’re celebrating his death. It’s pretty shitty.”

The Lost Riders arrived soon after to take her away. She tied a red scarf over her head to protect her hair.

“Don’t make me cry,” she told them.

At the church, the funeral directors folded an American flag over Ethan’s casket, and Maria began straightening the pins on his dress blues. Inside one of his pockets was a Mickey Mouse pin, as a reminder that he was still a kid. In the background, a slideshow played, with the photos falling into two main categories: Ethan with Maria, and Ethan with pretty girls.

Wearing a black dress with red flowers in her hair, Maria hugged and kissed a long line of visitors. Like Ethan, she had a way of smiling even when she hurt.

In the program was a psalm about the Lord as a refuge and a fortress, but she wavered on God’s existence. Before the diagnosis, she’d been a believer, but now she wasn’t sure. It was annoying to hear people say they were sorry, because the cancer wasn’t their fault. It was painful to hear them say that Ethan was in a better place, because his place was in her arms.

She took the podium early in the service, one of the first speakers to address the 400 some-odd people in attendance.

“Thank you all for loving my little man,” she said.

At the end of the ceremony, a Marine knelt down and handed Maria the folded flag, giving her the appearance of a war widow. The pallbearers carried Ethan outside and into the hearse.

At Diamond, Ethan’s friends and family ordered pitchers of beer and platters of wings and watched his pictures shuffle across a giant projection screen. Some played pool. Others chatted up women. Glasses clinked and waitresses moved around manically, as if not prepared for such a large crowd.

Across the room was the table where Ethan had played pool, the bar stool where he’d sat to open his birthday presents and the jukebox where he’d played the Charlie Daniels Band just 11 months earlier. This was the place they celebrated Ethan turning 12. Now, it was the place they felt the loss of 13, 14, 15 and all the years that would have followed.

Just before 6, a bagpipe player came to the bar and began to play “Amazing Grace.” Under the neon lights, Ethan’s friends lifted their drinks and the bagpiper marched back and forth through the room, one foot in front of the other, the song filling the air, and it really was the sweetest sound.

was diagnosed with leukemia at 7. Ethan wanted to bring a friend along for the ride.

The trip was important to Maria because she didn't want Ethan to have any regrets. She wanted him to see the waterfalls in Alabama and the desert in Arizona. She wanted him to visit with his grandfather, to hear her dad's stories.

When it came time, she wanted Ethan to have no doubt of who he was and where he came from. When he took his last breath, she wanted to know that her son had a full life, as full as he could get.