

THE *Supportive* POWER OF *Palliative* CARE



For patients like 3-year-old Samuel, focusing on quality of life can make all the difference.



STORY: CHRISTINA ORLOVSKY
PHOTOS: PAUL BODY

They say it's
not the years
in your life
that count,
but the

*life in
your
years.*

For Ami Doshi, MD, director of Palliative Care Inpatient Services at Rady Children's Hospital-San Diego and associate clinical professor of pediatrics at UC San Diego School of Medicine, these words drive her daily work with the medically fragile patients in the Hospital's Supportive Care / Palliative Services Program.

"Palliative care is a form of specialized health care for children and families living with serious illness," Dr. Doshi says. "The focus is to provide relief from symptoms and the stress of illness, with the goal of improving quality of life for the patient and family—maximizing quality while minimizing suffering."

While the term "palliative" may bring to mind hospice and terminal illness, palliative care can be offered at any time alongside disease-directed care, and should be thought of as an extra layer of support addressing the holistic needs of the child and their family. Working in conjunction with medical specialists, the palliative care team—which consists of board-certified pediatric palliative medicine physicians, certified pediatric palliative nurses, social workers and spiritual counselors—assesses each family's individual health care goals, helps them navigate difficult decisions and provides inpatient and outpatient resources.



Dr. Ami Doshi is inspired by the resilience of palliative care patients like Samuel, seen here with mom Ali Tebbs

"Our most important job is ensuring that the child and their family's hopes and values are shaping their care," Dr. Doshi continues. "Those goals differ and can change over time—whether one day it's simply to stay out of the hospital, or another to sit up in the wheelchair, or another to get back to playing soccer. As hopes change, we are there to make sure the plan is evolving with them."

While Dr. Doshi works with patients and families during inpatient stays, families also benefit from outpatient visits with the team's social workers, who serve as their advocate and support system—navigating Medi-Cal, reserving stays at the Ronald McDonald House, setting up SDG&E discounts or music therapy sessions, or simply giving the peace of mind that comes from knowing someone is there to help them if they're struggling.

"Everything we do is to support families when they're at home," says Ashley Henderson, a social worker with Rady Children's Home Care. "To address all the barriers that may exist, so they can function as well as possible for as long as possible. What makes palliative care so special is that we work as a team to support the family. We do our best work because we don't do it alone, and that makes the families feel like they're not alone. That's what drives me."

For her part, Dr. Doshi is constantly in awe of her patients and families. "They inspire me with their resilience, their grace and their strength," she says, "whether or not they get the outcome they were hoping for. It's a privilege to walk alongside these families and a powerful thing to be a part of these children's journeys."

Samuel Tebbs was born a fighter. Just by surviving the birthing process, he'd already won a lengthy battle. Diagnosed with pentalogy of Cantrell—a rare and severe disorder characterized by birth defects of the sternum, diaphragm, pericardium, abdominal wall and heart—at his mother Ali's routine 14-week ultrasound, Samuel faced a grim prognosis.

"We were given the option of abortion up to 24 weeks, but for us that was never an option," Ali says. "For the duration of my pregnancy I was closely monitored in the high-risk clinic. Instead of being immersed in the joys of baby showers and the dreams of raising him, we had to move forward with each new day planning to say goodbye to our precious son right after birth."

Ali, a first-time mom and patient at UC San Diego Health, and her husband, Jared, met with Krishelle Marc-Aurele, MD, a clinical assistant

professor at UC San Diego and Rady Children's outpatient palliative care physician.

"She was an amazing support to us through it all," Ali recalls. "A few weeks before Samuel was due, I was encouraged to call the funeral home to prepare, because I knew I would not be able to do it after birth, and she was there with grace and compassion to walk through it with us."

As Ali and her husband prepared for the worst, the palliative care team supported her along the way, even suggesting the most peaceful room for her to grieve after delivery, should he not survive the birth. "As strange as it seems, that was so very helpful to us—to talk it through

and begin to emotionally, mentally and spiritually prepare for the grief that was to come," she says.

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DR. AMI DOSHI

It turned out that Samuel had a plan of his own. Despite Ali's planned caesarean section at 39 1/2 weeks, Samuel decided to arrive a week early. Ali went into labor and was rushed in for an emergency C-section. To everyone's surprise, Samuel survived. Born with his intestines outside his body but his sternum intact, he was immediately placed in the neonatal intensive care unit at UC San Diego Health for five days before being transferred to Rady Children's.

"Everyone was so surprised that he survived the birth, and we thought, 'Maybe we can do this,' Ali says. "But we knew we had a long road ahead." Samuel's complications were extensive, and during his first

few months of life he faced surgery after surgery to repair birth defects, including undergoing a tracheostomy and becoming fully dependent upon a ventilator for sustaining life. "With his diagnosis and condition, there is no quick fix. We were just checking things off—fixing something and waiting."

Then at six months, Samuel went into cardiac arrest. "At that point we realized his heart and lungs were in a lot worse condition than we thought, and he might only have weeks to live," Ali says.

Once again faced with the devastating thought of Samuel's death, Ali and Jared returned to palliative care—this time, with Rady Children's inpatient team, led by Dr. Doshi. The couple consulted with Samuel's physicians, leaned on their faith and gave themselves a few days to decide on their new care plan—a decision they did not take lightly.

"You hear the word 'palliative' and if you don't know what it really is, it can have a negative connotation—like you're giving up on your child," Ali explains. "But that couldn't be farther from the truth. Palliative care really is about switching your goals toward your child's comfort and quality of life—realizing that

keeping him comfortable is more important than pushing for ‘normalcy.’ We had to realize there would forever be a ‘new normal’ for us and see that just maybe there was a greater purpose for our Samuel than we could have ever dreamed of no matter the length of life.”

Having made the decision to focus on palliative care, Samuel’s family was able to have new experiences with him that hadn’t previously been possible. He was weaned off intravenous medications and placed on medications fed through his nasogastric tube to prepare him to go home. He was able to be placed on a blanket on the floor of the NICU to have a “picnic” with his family. He was able to go outside for the first time, with what Ali jokes was “his whole caravan of caregivers.” And he was able to have visits from extended family and friends.

“These were huge things we didn’t think would happen, but Dr. Doshi and the whole palliative care team helped us, simply by asking what memories we wanted to make in the time we had with him,” Ali says. “Once we shifted our focus to not getting him better, but getting him stable enough to go home and enjoy what time we had—whether it was a couple of weeks or a couple of months—we knew that’s what ‘quality of life’ meant to us.”

In May 2017, 10 months after he was born, Samuel finally went home.

Today, Samuel is 3 1/2, continuing the fight, now not only for himself and his parents, but also for his little brother, who is nearly two. As a big brother who sometimes doesn’t want to share his toys but does love giving kisses, Samuel remains extremely fragile but, as Ali says, “he smiles through it all.” He accompanies his family to church every week, enjoys car rides to Julian and loves to feel the speed of the jogging stroller on his mom’s daily runs.

“For him it’s the simple things,” Ali says. “Breathing and eating are two of the simplest things humans do, yet he is dependent on machines to do both. Still, he’s happy and content. He’s such a special little boy, and the palliative care team helped us so much in realizing that and coming to terms with the severity of his condition.”

That, she says, is the biggest blessing of all. “The best way to define ‘palliative care’ is giving your child the best quality of life according to what your heart believes,” Ali says. “It’s not a death sentence. In our case, it’s celebrating our child’s life in the reduced quantity that it is, but also celebrating it for exactly what it is, enjoying the little things and knowing we have the support to help us do that. Dr. Doshi and her team are a godsend to us. It truly takes a village, and we’ve had so many hands in Samuel’s care that it’s been a true blessing to be part of the palliative care program.”

Julia Haith was a healthy, happy child, born at full term and meeting all her milestones. When she was diagnosed with type 1 diabetes at age 4, her parents were unprepared for what would follow.

“After that diagnosis, Julia just kept getting sick,” says her mother, Carmella. “She would fall a lot, and things just weren’t normal.”



IT TAKES A VILLAGE!

Samuel and his family (left) get plenty of support from social worker Ashley Henderson (right) and Dr. Doshi (below).



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**ALI TEBBS,
SAMUEL’S MOM**



Julia’s endocrinologist suggested the family see a metabolic specialist. That’s when Julia was diagnosed with Kearns-Sayre syndrome, a mitochondrial disorder that manifests in progressive paralysis of the eye muscles and other neurological symptoms. For Julia, who started demonstrating symptoms of the disorder at age 8, the effects were severe.

“She would have episodes where she was very lethargic and couldn’t talk,” Carmella recalls. “She would go into a non-medically induced coma for anywhere from three days to two weeks and then she’d wake up. But every time she experienced it, her body would decline a little and never recover what she lost.”

Julia’s disorder put her in the hospital two to three times a year, sometimes for months. As her disease progressed, the episodes became more life threatening. During one visit, her family was introduced to Dr. Doshi and the Rady Children’s palliative care team.

“When you think ‘palliative care,’ you automatically think end of life, which can be difficult if you don’t understand how the team operates. Dr. Doshi and her team became our rock,” Carmella says. “They knew Julia’s journey and her story, and they provided a support system that followed us through our hospitalizations and beyond. Dr. Doshi truly has a gift. She does everything in her power to cater to each child and their family. I always felt secure when I went to the Hospital because I knew I could call her at any time, and she’d be right there at the bedside.”

As Julia’s health declined and the thought of hospice was introduced, her family began to utilize the Hospital’s Supportive Care / Palliative Medicine home services to make weekly visits and deliver medication. Over the course of her illness, Julia’s family would alternate between hospice care and palliative care when her condition improved—all the while focusing on maintaining her quality of life.

“I think everybody’s perspective for their child’s quality of life is different,” Carmella says. “While we weren’t in denial about the severity of Julia’s condition, we also couldn’t lose hope that she’d get better. The palliative care team was able to support us and respect how we felt. They never passed judgment and they advocated for us. Sometimes I’d be mad, and they’d let me vent. And they always had tissues for me because they knew I’d cry. All of them took the time to get to know our family, provide the resources we needed and hold our hand through the whole journey. It’s a sad thing, but it’s also a blessing.”

Julia passed away six years ago at age 18. While her family keeps her memory alive by sharing her story, Carmella took her daughter’s legacy one step further by becoming a nurse after her death.

“Spending so much time at Rady Children’s, we got to know a lot of nurses personally. Watching them and the care and love they gave to Julia was inspiring,” she says. “I thought, *I can give back.* Nurses are such a big part of your healing process. For me, it’s therapeutic to take what I went through and use it to help people.” ■

Supporting More Families Thanks to

Philanthropy

When Elaine Galinson read about a Minnesota pediatric inpatient hospice care program in the *New York Times Magazine*, she found it incredibly moving. “I’ve been fortunate to have three children and seven grandchildren, none of whom have required services like those. We’ve never been faced with difficult choices regarding life-threatening disease.” The story ignited a thought in her: What are the options for patients and families here in San Diego who are experiencing difficult care decisions?

Galinson contacted Rady Children’s to learn more, and discovered that not all families desire the same level of palliative care. Some want a full inpatient experience, while others prefer to care for their child in their own home; many desire a combination. “Rady Children’s gives families informed choices about treatment and care,” she says. “What’s best for each family is a very personal choice; this program can help parents determine what relieving suffering and improving quality of life means to them. That was inspiring and made absolute sense to me.”

Thanks to an estate gift left by her parents, Beverly and Joseph Glickman, she invested in supportive care services by endowing the Galinson-Glickman Family Chair in Supportive Care at Rady Children’s. “My hope is to expand services to all families who find themselves needing palliative and supportive care, and for each family to have the most meaningful experience possible with their child for as long as they’re able.”

Join Elaine Galinson in extending the reach of Rady Children’s inpatient and home-based supportive care services. Visit radyfoundation.org/donate/palliative-hospice-care.