

As his sight slips away, a 9-year-old Lewisville boy finds successes more challenging

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About death, poet Dylan Thomas wrote: *Do not go gentle into that good night*. For 9-year-old Zach Thibodeaux, a different kind of night is approaching: the erosion of his visual connection to the world around him.

Nearly two years ago, the Lewisville boy was diagnosed with cone-rod dystrophy, an incurable disease gradually destroying his retinas.

At 9, he and his peers are latching onto activities physical and intellectual, discovering the things they like to do, discovering themselves. New skills and successes spark confidence that helps shape social development.

But for Zach, who has minimal sight left, the prospects are more challenging. His family encourages him: *Zach, you can do anything you want*. At the same time, they're wary of setting him up for disappointment.

Some days are good, some not. One day, he and his mother, Johanna Uek, were at Tuesday Morning, in the toy section.

What's this game, mom? Do you think I can do this one?

"All these games are for sighted people," Uek said, recalling the moment. "He wants to play. He just doesn't think it's fair."

Like his mother, Zach is highly spiritual, a gifted child whose grades and sweet-tempered demeanor began to suffer until he was properly diagnosed. Since then, he has excelled at Braille and reclaimed his academic prowess.

Still, as he begins to comprehend the realities before him, anger occasionally sets in. He hates the idea of being thought incapable. He resists the label of blindness being thrust upon him.

As his world goes dark, he is — in the poet's words — raging, raging against the dying of the light.

'Never let go'

"I believe judo — if you practice enough — you really don't need eyesight."

At 72, Kaoru Ishii has the build and complexion of a man decades younger. The fifth-degree black belt was talking about the prospect of teaching Zach the martial art he has studied for five-plus decades.

While some martial arts focus on creating contact, he said, judo is more defensive: Students learn to capitalize on their foes' momentum, felling them with throws rather than blows.

The initial grip on an opponent's robe, Ishii said, is key, allowing one to sense actions before they happen. "I can sense through the uniform," he said. "His grip will change, so I can tell what he's going to do."

Ishii's sessions, held at his Garland studio, are intense and nonstop. As his white-robed students stretched and tussled, Ishii spent the time aping the drills or lifting dumbbells.

After just weeks, Zach still struggled, good with practiced routines but faltering as Ishii introduced new moves. For those, the sensei had to physically guide Zach's limbs through the motions.

"Each time we come, he picks up a little more," said Adam Thibodeaux, Zach's father.

Student Emily Baudot, 18, had emerged as a class leader — faster, stronger, focused as a fighter pilot. She'd taken Zach under her wing, offering advice:

Don't let go.

At this point, the smart thing to do would be...

You don't have to go where I pull you.

Over and over, she flipped and pinned him. "Never let go," she told him. "I was able to do whatever I wanted."

The determination in Zach's face was evident as they grappled, trying with all his little-boy muscle. He grimaced; she was stronger.

After several tries, the smaller Zach heaved Baudot over his shoulder. "Yes!" he said excitedly.

"Good job. Really good," Baudot said, smiling. "That hurt."

"Judo's a lot about momentum," she said later. "I'm trying to get him into the mindset of not actively resisting."

Losing pastimes

The boy who loved video games can play them less and less. Zach has to stand right in front of a giant TV monitor placed as low as it can go.

Soccer, too, has become difficult. Zach's sight has been reduced to what amounts to a singular sliver of sight in one eye and scattered starry bits in another.

Strength and exercise will be crucial as he ages, advocates for the blind say: Obesity and inactivity especially plague visually impaired adults.

Mindful of that, the state's Division for Blind Services, part of the Texas Department of Assistive and Rehabilitative Services, sponsors an annual sports festival for the state's blind children.

Juanita Barker, the division's programs management director, said the benefits of exercise aren't just physical. "It's a huge confidence builder when they see they can participate like any other kid," she said. "Think of what it does for self-esteem and social skills."

Sports options for the blind are increasing, either via original games like goalball — a sort of cross between air hockey and soccer, played on a court — or others that have been adapted. Beep ball, for instance, is a baseball-like game in which the sounds of the ball allow blind players to track its whereabouts.

Zach, though, isn't ready for that. When his optometrist, Stephanie Fleming of Dallas Services' Low Vision Clinic, asked whether he'd tried playing beep ball, he quickly changed the subject.

"He's apprehensive of doing things that are just for blind kids," Uek said. "He doesn't want anything to do with it right now."

Finding his niche

And so, Zach's family is encouraging other, mostly individual and tactile activities: Besides judo, Zach has found joy in swimming and ceramics. Piano lessons may follow.

"We're trying to find something so he can find his niche," Uek said.

Art had been a source of drama for Zach, whose creations suffered from his struggles to see. But ceramics' molded shapes and the free-form painting they encourage have fired him up.

"It's basically from your heart," his mother said. "I think it's relaxing for him. He likes the fact that it goes in the fire and becomes something different."

Last month, Zach was among a dozen kids in a ceramics workshop at Lewisville's Herring Recreation Center, applying glaze to clay mugs and vases.

"It's to make it shiny," Zach explained. "But you don't want it to be too shiny or too dull."

Art instructor Marynell Kaufman led them through the motions. "What you're painting with right now is glass," she said. "It's just in liquid form. It's transparent. But the part underneath is ..."

The students sat, quietly.

"O — o — opaque," Zach said, filling in the blank.

"Opaque," Kaufman confirmed. "Thank you, Zach."

She continued. "OK, here's the hard part. Do I have all eyes on me?"

She showed them how to glaze the interiors of their vessels with a swirl, then came over to Zach to guide his hand through the motion.

"This is going to be my Christmas cup," Zach said. "I'm going to have hot cocoa."

Zach has also found fulfillment caring for his Labrador retriever, Natura, provided through a program called K9 Buddy.

For her service, Natura, who joined Zach on New Year's Day, was nominated for the American Humane Association's Hero Dog Award.

Uek, too, got her own puppy, an English bulldog that is now Natura's playmate. But one day at home, Zach stepped in a puddle that the dogs had made.

He became furious.

He started to cry.

He locked himself in the bathroom.

Why? Why? Why don't I see?

"Moments like that are hardest for him, and for us," Uek said.

All along they have told themselves, and others have reminded them, that God has a plan.

You can help people, Zach.

Raging, raging.

I don't want to help people right now.

A belt is earned

But this, too, passes, and by last month, Zach had earned his first belt in judo, a milestone for a kid who struggled to do push-ups two months prior.

"He thought that was something that was so far away," said his stepfather, Joey Uek. "For him, that was really kind of cool."

Zach had begun to trust his other senses, to follow Ishii's advice.

In class, he and Baudot grabbed each other's lapel with one hand and an elbow sleeve with the second. Baudot yanked Zach across the mat like a ballroom dancer, trying to trip him up.

The exercise tested his balance. He closed his eyes to stay loose: Tighten up, and she could use that against him.

At first Zach had been afraid to close his eyes, struggling to get by with the little sight he had left. But the split seconds it cost to interpret what he saw made him vulnerable.

Finally, he just let go and relaxed.

Said Ishii, his sensei: "He is no longer afraid."

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