

about and think about long after it's over.

The moment builds as they swirl through the water. They are singing with their counselors. *Ring around the rosie, pocket full of posie . . .* When they get to the "all fall down" part, they duck beneath the surface.

Whitney and William emerge, drenched and startled. Immediately, the counselors start cheering and applauding, and the campers join in. All over the pool people are yelling and clapping for William and Whitney. "Oscar, I did it!" whoops William to his friend, who is floating nearby.

"Great," yells back the normally silent Oscar, who has forgotten he can't talk.

24 Hours A Day

At night, the parents gather outside the cabins on the patio to talk about life with their children. They talk about failed attempts at getting them schooled. Practically all of them have had to fight battles to get the public school system to take their kids. Practically all of them say their kids are miserably behind grade level, not because of mental deficiencies, but because the kids spend so much time in critical care, and the school systems all over the country seem unable to accommodate them when they are well enough to learn. Some go to public school, but most are like Oscar. The only schooling they get is a couple of hours of homebound tutoring a week.

The parents sit under the pines while camp counselors serve them *cappuccino* and brownies. Delores, Oscar's mother, comments on how nice it is to be waited upon and pampered since it is she who is always doing the waiting and the pampering.

"I went back to work this year," says Charlene, the mother of Garret Frey, 9, who was totally paralyzed in a motorcycle accident when he was 5. "I had to have a life of my own."

Delores listens intently. Last year, she and Oscar's dad got divorced. Delores has started back to college and needs encouragement to stick with it. She is trying to have some goals for herself, without feeling guilty. One of the members of the camp staff says something about how difficult it is to find the right balance between being

supportive and being overprotective.

Then the parents' conversation turns to the lack of privacy in their homes with nurses constantly coming and going. William's mother says she asks the nurse to step outside so she and her husband can argue. Garret's parents say they yell at each other in front of whoever happens to be there.

"We're not perfect; we're human," says Jerry, Garret's father. "We figure if Garret can accept his disability, the least we can do is accept who we really are."

There is talk about the kids approaching puberty and how to deal with it. A sadness comes over the parents when they talk about their kids' futures. Some of the children are not expected to get better. Most have degenerative diseases. Derrick's mother, Francine, reminds the other parents that her son was diagnosed with muscular dystrophy years before, and she was told he would get worse and worse until he died. Two years ago he came to camp, and he had so little muscular control, he couldn't even open his eyes. But now he has enough strength to propel his unmechanized wheelchair by hand. He can even take a few steps. Simper thinks he'll be totally off the ventilator by the end of the year.

"That child of mine," says Francine, "is a miracle boy."
"All the kids seem to get better at camp," says Barry's father.

For meals, the campers and their families line up at long tables in the mess hall. Some of the kids hoc into ziti, Italian sausage and salad. All of the parents and brothers and sisters do. But most of the kids sit at the camp table, amid all of the eating, while a nurse or parent fills their feeding tubes with canned formula. One boy, 3-year-old Jeremy Martinez, insists upon an empty plate and a spoon. He scoops the spoon along the plate and puts imaginary food in his mouth while his mother pours a chalky liquid into his feeding tube.

Late nights in the cabins are like nights in intensive care. Nurses and parents are up, off and on, all night. Alarms scream. There is the constant clicking of dials and the sound of people gurgling. Gauges are periodically checked. Most of the children must be turned and suctioned every few hours. Nurses go from bed to bed catheterizing bladders, inserting suppositories and

changing soiled pads.

Just to get one child ready for bed takes hours. The sponge baths. The bronchial dilators. The vibrating, pounding on backs and suctioning to free plugs of mucus. The catheterizing, the hydrating, the careful cleaning around incisions, the administering of medications, and more medications.

When you see the kids dressed and hot-rodging around in their wheelchairs, despite the ventilators and equipment, despite the obvious disabilities, you have no idea what goes into their care. But when you see their frail atrophied bodies being handled, rubbed and manipulated, as they lie in bed exposed and helpless, you get a sense of just how difficult it is for them to keep going. You also get a sense of what truly great sports they are. And how little the physical self has to do with who anyone is.

Easy Sailing

It is the fifth day of camp and the kids are sailing, clipping along with their hair blowing and their faces full tilt in the salt air. Past Vizcaya and the colorful Brickell condos, and under the Key Biscayne bridge. Oscar is fascinated by the massive concrete columns and the underside of the bridge — the highest and most massive ceiling yet. Gulls and cormorants circle the catamaran's massive sail as the boat glides through bright sun and jade-green water.

The kids on ventilators from Broward's Children Center — Jason, Tish, Buddy and Felicia — have joined the camp for a day. Jason Shomer, 22, in rainbow-mirrored sunglasses, is the coolest thing going. He does not say it to the younger kids, but his presence does: Look at me. You can have a life. He whips his motorized wheelchair around with impressive flair, tells true stories of driving it around town as if it were a car.

Jason is so disabled he has to live in a hospital, but he is so able, he's dead set on coming up with the money to go away to college by himself — to Edinboro State College in Pennsylvania. They have a dorm there, he says, that is staffed by nurses. He plans to become a high-school teacher.

The huge catamaran motors down the channel, into