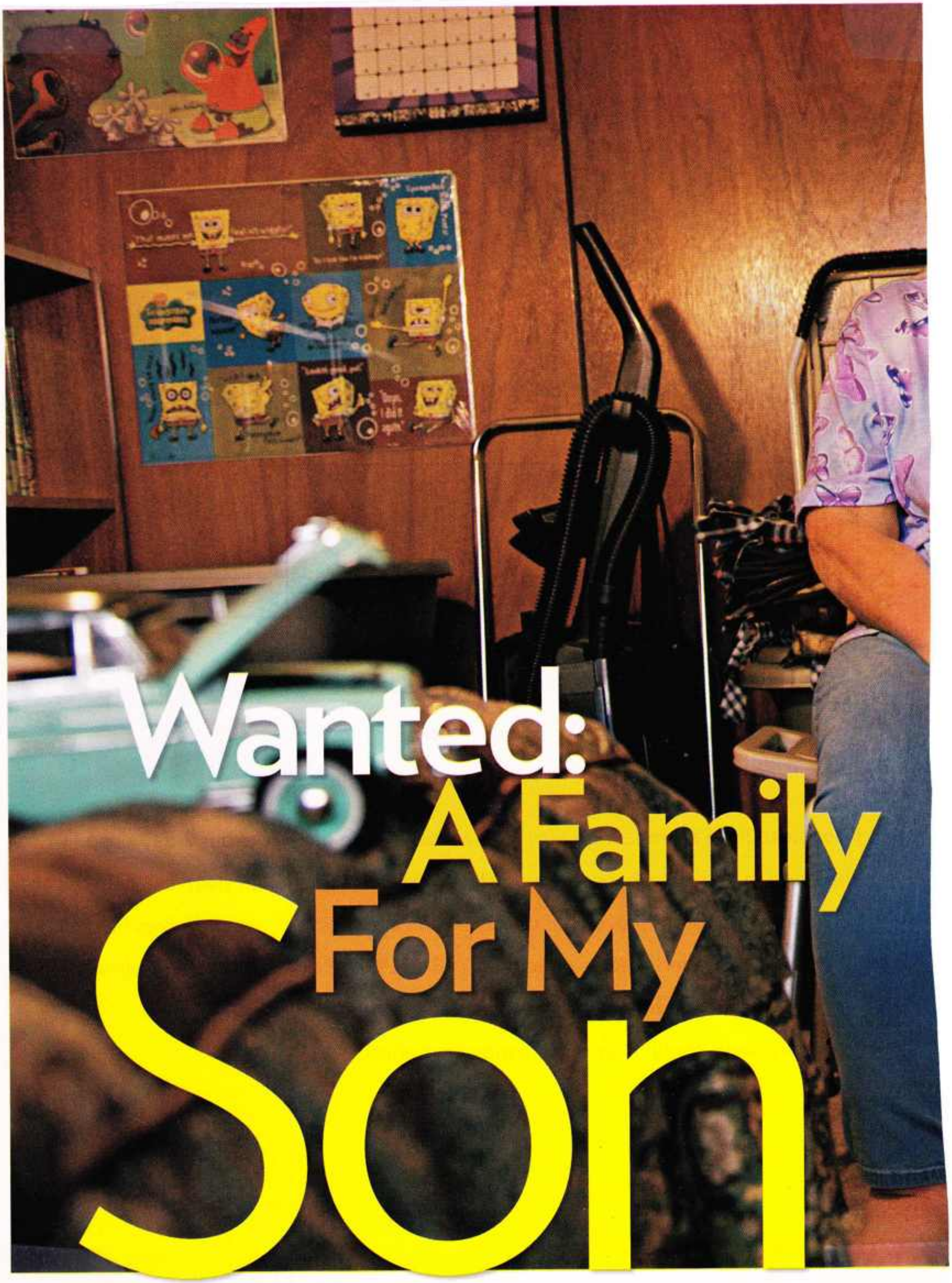
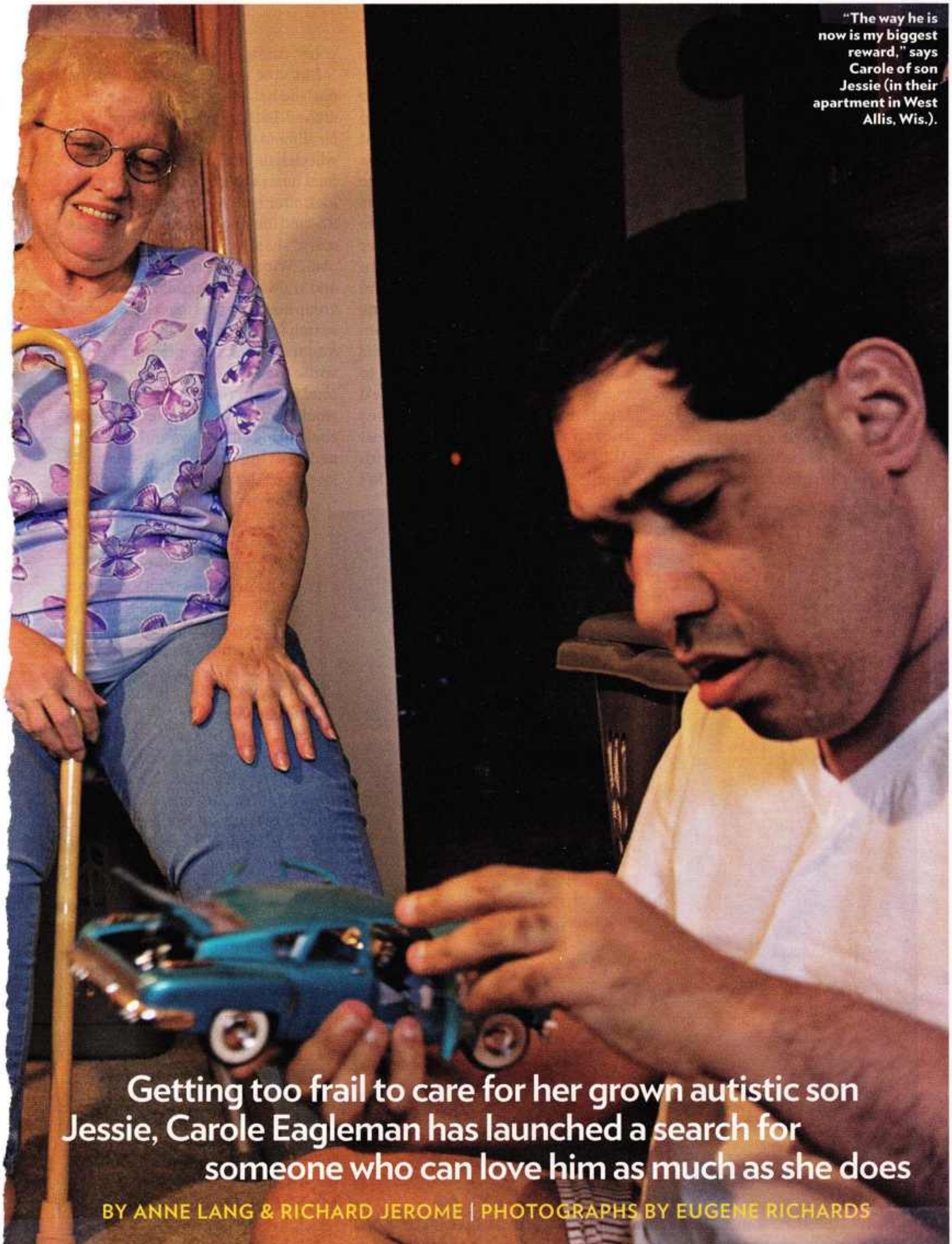


Wanted: A Family For My Son



"The way he is now is my biggest reward," says Carole of son Jessie (in their apartment in West Allis, Wis.).

Getting too frail to care for her grown autistic son Jessie, Carole Eagleman has launched a search for someone who can love him as much as she does

BY ANNE LANG & RICHARD JEROME | PHOTOGRAPHS BY EUGENE RICHARDS

She remembers the moment he was born, when he came out screaming and she gazed into his deep, brown eyes. "A breathtakingly beautiful child," 30-year-old Carole Eagleman wrote in her journal as her new son's life flashed before her: Jessie as a euphoric high school graduate, as a serious-minded working man, as a proud and handsome bridegroom.

She soon understood it was not to be. Jessie was autistic and suffered from epilepsy; her job in life would be to take care of him. And so she did, learning to delight in the boy he was: a gangly kid with a contagious giggle, who loved all things Elvis, *The Three Stooges* and his stuffed-tiger "bed buddies." As Jessie grew into a young man, mother and son found joy in their daily routine—swapping silly jokes as she'd devour a Stephen King thriller and he'd play with his miniature cars; glued for hours to videos, *CSI* or Animal Planet. "We'd laugh day and night," says plain-spoken Carole, who lives in West Allis, Wis. "Jessie goes to sleep with a smile and gets up with a smile. He's goofy, funny and precious."

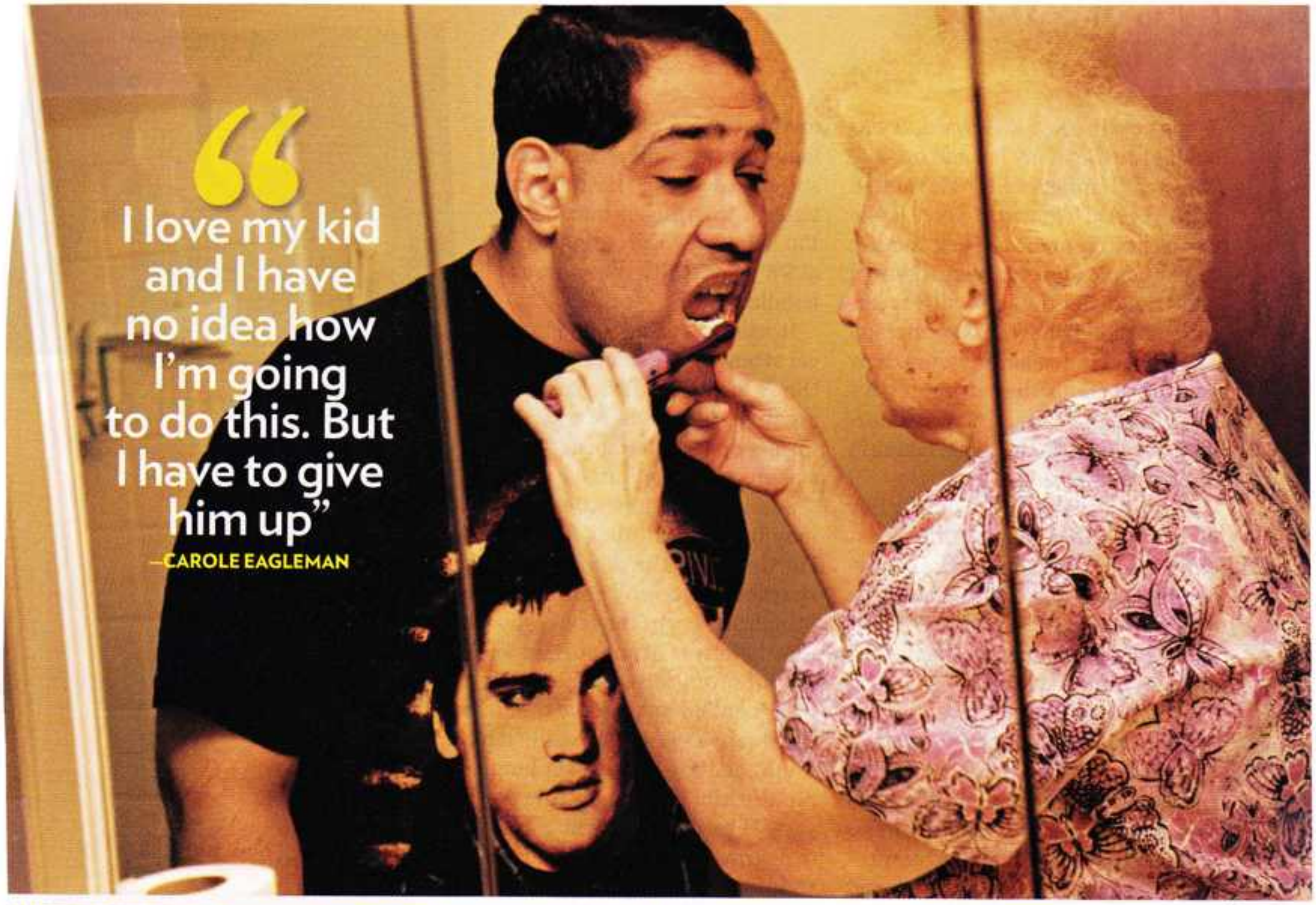
But now at 67, Carole knows the day she has long dreaded has finally arrived. Battling painful neuromuscular ailments that often confine her to a wheelchair, weakened from two near-fatal heart attacks, she can no longer look after her only child—who is now 37—and lifelong companion. "It's very scary," she says. "I didn't have a backup plan." With no close relatives to call on, and knowing Jessie couldn't cope in a group home, she has launched a public search for a family that will take him into their lives. In September Carole wrote to the *Milwaukee Journal Sentinel* for help finding a family "who would have an empty room where he could bring all his toys and books . . . and most importantly . . . who would love him." Jessie is well aware of his mother's mission, though when asked about it, her normally chatty son just bows his head. "I've never talked behind his back—he knows what's going on and why," says Carole tearfully. "He can see the physical pain in my eyes, and it wipes the beautiful smile off his face."

Carole's dilemma is hardly unique: According to the Arc of the United States (formerly the Association for Retarded Citizens), more than 700,000 American adults with autism or some form of intellectual disability live with family member caregivers over 60; parents agonize over what's to become of their children when they die or grow too old or sick to carry the load (see box). "There's not much out there in terms of services for adults with autism, so parents like Carole are left in a panic," says Marguerite Colston of the Autism Society of America. When Jessie turned 19, Carole put him on her county's waiting list for a group home; over time she feared he'd be miserable in that setting. "They called when he was 32," says the onetime executive secretary who gets by on $1,672 a month in Social Security and veteran's pension from Jessie's deceased father, whom Carole divorced when

Carole and Jessie: A Life Together

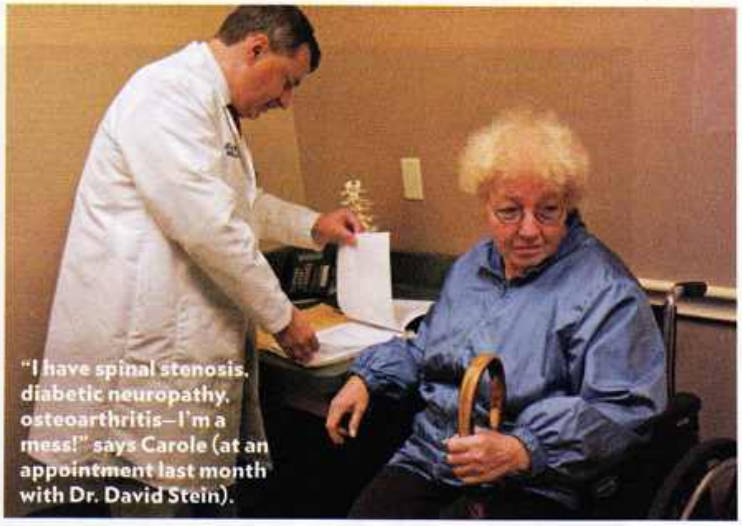
As a baby and toddler, Jessie (left, in '71 and, at right, in '73) "would slither away when I held him in my lap," Carole says.

"Carole would move heaven and earth for Jessie [in '81]," says family friend Ann Morgan.



> "I love my kid and I have no idea how I'm going to do this. But I have to give him up"
> —CAROLE EAGLEMAN

"He loves errands," says Carole (with Jessie at the supermarket and, above, helping him brush teeth).



"I have spinal stenosis, diabetic neuropathy, osteoarthritis—I'm a mess!" says Carole (at an appointment last month with Dr. David Stein).

Jessie was 2. "By then I couldn't pull him out of a happy home."

She made it that, despite daunting odds. All had seemed well when she gave birth on Aug. 14, 1971. But by the time Jessie had reached 18 months, she'd sensed something was wrong. "Why won't my child look at me?" she wrote in her journal. "Why is he so stiff when I hold him?" As a toddler, he drove her to tears—kicking, biting, scratching, screaming. "If people visited, I'd give him a magazine. He'd sit and tear it into tiny pieces. Once he went through a whole JC Penney catalog."

Determined to help him, she took him from doctor to doctor. Finally, at 2, Jessie was diagnosed with autism at a time when the condition was little understood. "My God!" Carole wrote. "My son will never be normal!" Still, she pored over books and scholarly articles and reached out to other parents, eventually helping found the first Milwaukee chapter of the National Society for Autistic Children. Despite twice-weekly speech therapy, Jessie never spoke, even after entering a special-ed program at 4.

Then one day the principal called: Jessie had suffered a seizure. "I was terrified," Carole recalls. "I didn't even know what that was."

Remarkably, one doctor believed, that seizure seemed to trigger something strange and wonderful in

Jessie's brain. Days afterward, "I was holding Jessie in my lap and he said, 'Wa-wa,'" Carole recalls. "He wanted water! I cried like crazy." Soon Jessie was forming sentences. Then another revelation: Jessie could read. His mom had tried teaching him with flashcards. "I didn't know he was catching on. He started reading newspaper ads to me." He also had an impressive knowledge of TV stars. "It was amazing," Carole says. "He'd been taking in information all along."

Accepting him for the quirky boy he was, she took delight in his passions—word puzzles, action movies ("Bruce Willis is No. 1!" he tells a visitor) and chores, or "J-O-B-S," as he calls them; he has nicknamed the vacuum Ernie the Eureka.

Still, there's much he cannot do. Though he attended special-ed classes in mainstream schools until he turned 21, basic arithmetic is beyond him; he has never held a job. He dresses and feeds himself, but Carole must help him bathe, brush his teeth and use the toilet. And though he takes medication to control his epilepsy, every couple of months he suffers a seizure. "He holds me tight, digs his fingers into me like I'm a lifeline," Carole says. But at 5'8" and 225 lbs., "he's hard to handle now."

It will take more than physical strength to replace Carole. "She's loving, selfless, exceptionally creative," says Sue Marks, Jessie's former speech therapist. "She made a happy world for him."

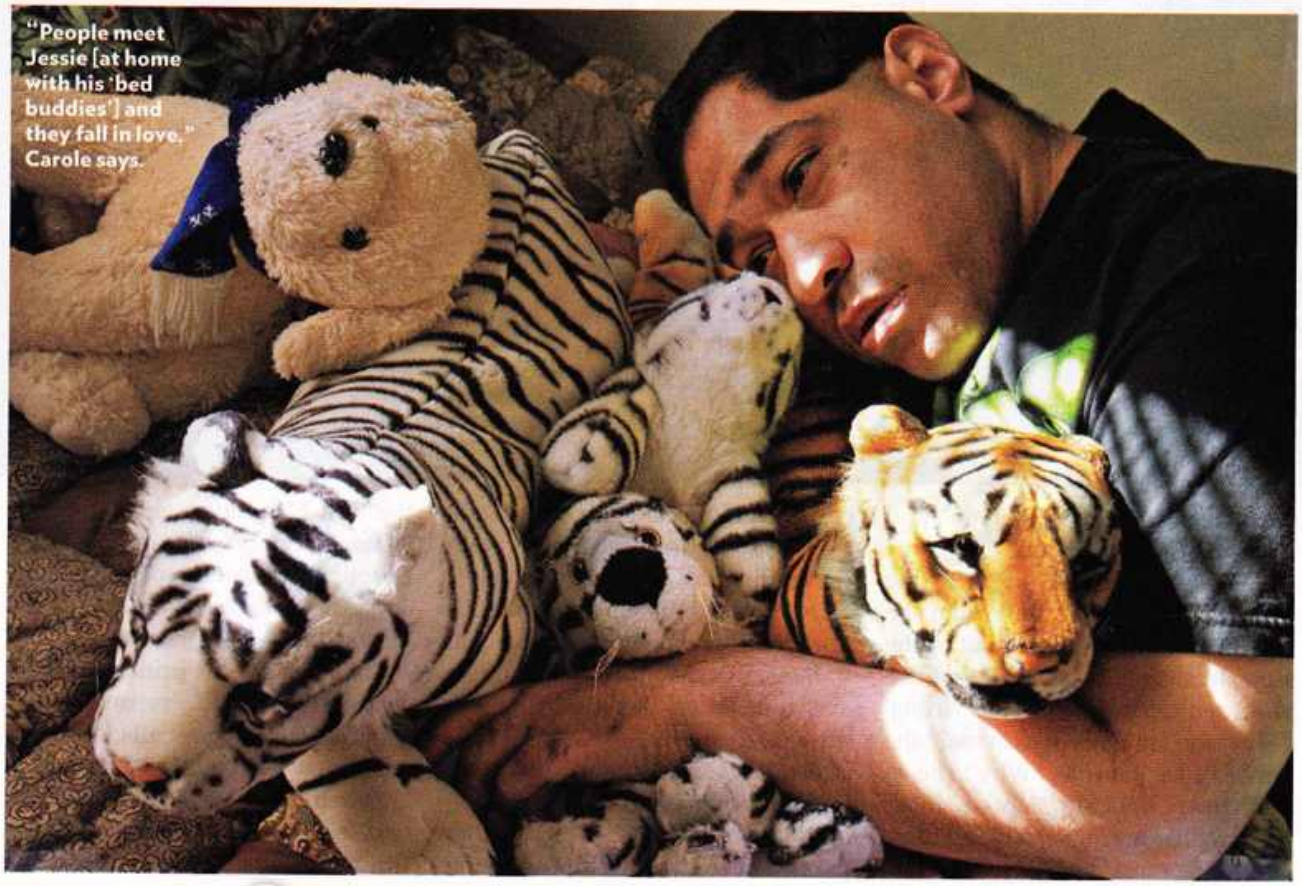
Soon, Carole hopes, Jessie's smile may light up another family's life. Her letter to the *Journal Sentinel* sparked a piece by columnist Jim Stingl. She keeps the few responses, mostly letters of support, in a folder and often rereads them. Illness hasn't dulled her resolve that when she finally says goodbye, she'll have found her boy the perfect home. "I picture him with all his things," she says. "I see a couple who miss their own grown children, who are ready to love Jessie. I know they're out there. I just know it." ●

Getting Help

Families in Carole's situation have a few options for placing loved ones:

- Supervised state or county group homes
- Staying at home with a paid caregiver
- Parent cooperatives: Families pool resources to create a staffed group home
- Residential assisted-living: Large facilities with medical staff

For more guidance on placement: **autism-society.org** or **nationalautismassociation.org.**



"People meet Jessie [at home with his 'bed buddies'] and they fall in love," Carole says.

To get in touch with Carole Eagleman, write to P.O. Box 14453, West Allis, WI 53214-0453.

MailBag

> **"In spite of the challenges he is facing, Michael J. Fox knows exactly what's important in life"** **Stacey LeBlanc** Gilbert, Ariz.

MICHAEL J. FOX

Many people have been diagnosed with Parkinson's disease, but Michael J. Fox has shown the courage to talk about it. He could have quietly lived out his life, but he made the decision to share his experiences and struggles. His insights shine a spotlight on the need to cure this disorder. By putting a face on Parkinson's, Michael is truly making a difference.
Kelly Rodono Torrance, Calif.

Thank you for the inspiring story on Michael J. Fox's ability to cope with Parkinson's and enjoy his life. The article presented an honest and detailed picture of someone dealing with this terrible disease. Also, the love that Michael and Tracy feel for one another is apparent in the incredible photos.
Maryanne Richards Carmel, Ind.

Growing up, my father was my biggest hero. Dad lost his 20-year battle with Parkinson's about a year and a half ago. After reading your story about Michael J. Fox's positive attitude and the research he is funding, I'm happy to say he is my new hero.
Gretchen Furlong Farmville, Va.

It was a joy to read about Michael J. Fox's zest for life. Times are tough, but we should all try to donate whatever we can to help find a cure for Parkinson's.
Raquel Hanon-Boujo via e-mail

SUICIDE ON THE WEB

What has happened to us that we think we can just sit back and watch someone die and not do anything about it? My heart aches for this young man, who was obviously reaching out in his last few hours while no one bothered to help him. Shame on all of us.
Kelly Decker East Wenatchee, Wash.

After reading this article, I'm more disappointed in the human race than I ever thought possible. I can only wonder how the people who logged on and did nothing can sleep at night.
Shelley Magnuson Colorado Springs, Colo.

SHENAE GRIMES

As a person who has never weighed more than 110 lbs., it was refreshing to hear *90210* star Shenae Grimes talk about the same issues I've had to deal with. I appreciate her giving a voice to the many women who are naturally quite small. Thanks for showing the other side of the story.
Tara Huntley Edwardsville, Ill.

CAROLE EAGLEMAN

Your wonderful story about the dynamic between a loving mother and her autistic son moved me to tears. During a time when most of us are worried about what gift we should give or receive for Christmas, Carole Eagleman is concerned about the most important thing in the world: the well-being of her child. This article made me see that family is what matters most—not only during the holidays, but all year round. I truly hope for the best for Carole and Jessie.
Kristina Zarbos Baltimore, Md.

KID CRUSADER


People HEROES AMONG US
She Helps Feed Thousands of Strays
Mimi Ausland, 12

Many readers were inspired by the story of Mimi Ausland, the 12-year-old girl from Bend, Ore., who launched two trivia-based Web sites—freekibble.com and freekibblekat.com—to help animal shelters facing food shortages. "It's a great way to show kids they can do something for animals from home," says Kristen Fuller of Wayland, Mass., who answers questions with her 7-year-old son Ryan. Now 9,000 more people are playing on Mimi's Web sites daily, resulting in some 500 additional meals every day for homeless cats and dogs. Mimi is also working with *National Geographic Kids* to get other children involved through a network she calls Kibble Krusaders.

WRITE US

TO CONTACT EDITORIAL: Send a fax (212-522-0794), e-mail (editor@people.com) or mail (Letters to the Editor, PEOPLE, Time & Life Building, Rockefeller Center, New York, NY 10020). Letters should include the writer's full name, address and daytime phone number and may be edited for clarity and space.