

Matt + Annie

Couple overcoming obstacles together, with love and support of family and community

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Matt Wilcenski is rigid behind the steering wheel. He does not fumble with a cellphone or the stereo, which is softly surging through a Shania Twain CD. He does not chat with his wife Annie, strapped into the passenger seat, as the steel-gray April morning slides by on their commute from Delmar to Albany's Empire State Plaza.

Every single molecule of Matt's body is focused on the road, like it is a magnet and he is built entirely of metal shavings. He knows that driving, like life, is full of surprises. The kind you can't plan for, no matter how you try.

"Matt!" Annie says, spotting a white Subaru nosing uncomfortably close as Matt turns left, joining the dense commuter traffic along Delaware Avenue. Matt steers away, avoiding a possible fender bender.

In such ways, trouble always lurks. It is never further than one bad decision, one momentary lapse of attention, one switchback curve you couldn't have seen coming.

For people like Matt and Annie -- homeowners, eight-to-fivers, nearly newlyweds -- life is lived along a narrow ledge between crisis and commonplace.

For people like Matt and Annie -- high-functioning developmentally disabled -- that ledge is narrower than it is for most people.

For them, the simple part was falling in love.

Ed Wilcenski Jr. knew his younger brother, 27-year-old Matt, had met a woman, but it didn't really hit him until later that night, seven years ago.

Matt had invited Ed and his wife Christine out to dinner at Macaroni Grill to introduce them to Annie. They all had glasses of wine and sat down for dinner. At some point during the evening, Ed saw out of the corner of his eye that his brother and Annie were holding hands under the table.

Wow, Ed thought. I'm on a double date -- with my little brother.

It was a thing he thought might never happen. For one of the few times in his life, Ed -- a Clifton Park attorney who specializes in laws affecting the developmentally disabled and their families -- couldn't figure out what to say next.

On the ride home with Christine later, that wasn't the case. The questions tumbled out.

Will Matt and Annie get married? Where will they live? Will they work it out?

And, most of all:

How cool is this?

Matt met Annie Giglio one day in the late summer of 1999 on the shifting deck of the Captain J.P. cruise boat. They were both attending the outing as part of a group from Wildwood Programs, a Schenectady agency that offers services to adults and children with learning and developmental disabilities.

She was a year Matt's senior, cheerful, with an easy laugh. She had a good job working as a clerk for the Department of Motor Vehicles, putting together paperwork that was shipped out to judges in Buffalo. She'd grown up in Newburgh, but her family had moved to the Albany area because of the lure of services and to get her in the special education program in the Guilderland school system.

Matt was tall and quick with compliments and humor. A Poughkeepsie native, his family had made the move north for similar reasons. He volunteered with the Delmar Fire Department and was a full-time kitchen worker at the Marriott on Wolf Road, a job he took so seriously he routinely got to work a half-hour early.

Both families were Catholic, and rabid Yankees fans.

A month later, Matt and Annie met for their first real date, at the movies at Crossgates Mall. Annie wore a dress, and her father, Charlie, dropped her off. She was 28 and it was the first date she'd ever been on.

Annie can't remember the movie they saw.

Her attention was elsewhere -- on the man she already knew she wanted to marry.

Charlie and Pat Giglio had thought Annie might never meet someone. But, not long after she and Matt began dating, Charlie got a window into what his daughter had planned as they drove up Western Avenue one day.

"Are we Catholic or what?" Annie asked.

"Catholic. Why do you ask?"

"Oh," she said. "Matt and I were trying to figure out what church to get married in."

By the time Charlie and Pat formally met Matt's parents, Ed Sr. and Mary Wilcenski, it was clear the families would be seeing a lot more of one another.

Despite Matt and Annie's achievements, their disabilities would always make them vulnerable -- even more so as they graduated to more independent living. For the couple, children would not be an issue, since Annie had made the choice to have her tubes tied in her mid-20s.

But a learning disability is forever.

"It wasn't like once they're married, they're on their own," said Ed Sr. "For someone with a learning disability, age doesn't matter. You'll always be needed."

Charlie had seen the types of things his daughter could fall prey to.

A few days before the wedding, he spotted a recurring \$100 monthly charge for a local gym during a review of Annie's checking account. He asked Annie about it.

She said she'd gone to check out a gym in the mall. The salesman told her they had a special, and that he could sign both her and Matt up. Annie said she needed to check with her father. The salesman asked her why. "You're over 21," he said.

Charlie went to the gym to talk to the manager. Ultimately, Matt's mother took up the flag, arguing all the way to the company's corporate level before the charges were canceled and refunded.

After two years of dating, Matt popped the question. He was so nervous, he forgot to get on one knee.

Matt and Annie headed to the altar, and toward largely unmapped territory -- of the heart, and of the Social Security disability system.

They married on June 26, 2004 -- Yankee Derek Jeter's birthday.

By then, Pat Giglio's wedding planning book -- representing nearly two years of work -- was heavy enough to flatten a foot. More than 200 people attended the formal reception at the Albany Country Club. Aside from Ed Jr. and Annie's brother, Tom, and his fiancée, the wedding party was made up entirely of Matt and Annie's friends from Wildwood.

The couple then moved into the Delmar townhouse they had bought the month before, through a New York grant program that helped people with disabilities make down payments on homes. With the legal changes that came with marriage, a financial problem arose -- unique to Matt and Annie's new living situation.

The funding for the long-term services that helped Matt and Annie live independently had been paid for largely through Medicaid. When Annie married, her income combined with Matt's pushed her over a financial threshold, making her no longer eligible for the services she'd been receiving -- and which were far too costly for her to afford outright.

"In a sense, it's a marriage penalty," said Ed Jr. "For people like Matt and Annie, who can work and save money and make independent financial decisions, that was an impediment to living independently and being married."

Even for Ed Jr., whose job required him to navigate the often labyrinthine system, it offered a challenge. Ultimately, Ed found a state entitlement program with a more liberal work-incentive program, which allowed for a higher income level and also let the couple set aside some of their earnings in a trust to pay for services.

"They don't need a lot, but their failure to access the amount of help they do need could really result in disaster for them," Ed said.

Because of their vastly different work schedules -- Annie working weekdays, Matt often working weekends or nights -- service coordinators from Wildwood met with them separately each week to help them manage household responsibilities.

Life fell into a comfortable rhythm.

Until January 2006, when Matt was unexpectedly laid off from his job.

He had been with the company for nearly a decade, working up from \$7 to \$12 an hour and rarely missing a day to sickness or vacation. But the hotel had been bought by a new company. A good portion of the kitchen staff had gotten pink slips.

Matt's entire demeanor changed. Ed could tell his brother was stressed, his mind always elsewhere even when he was in the middle of a conversation. His sense of humor seemed drained.

But Ed knew how resilient his brother was. Matt knew, more than most people ever could, what a true challenge was -- and that it could be overcome. Matt's job coordinator at Wildwood, Kim Lipscomb, scrambled to find him interviews. Ultimately, just as Matt's seven weeks of severance pay were due to run out, an interview Kim had set up even before Matt had lost his job came through.

In March, Matt began work as a clerk with state Office of General Services in the Empire State Plaza, delivering mail inside the Plaza, in the same complex where his wife worked.

It is April 13, and Matt and Annie are meeting at their home with Rich O'Neil, a Wildwood service coordinator. O'Neil has worked with Matt for two years and is now -- for the time being -- seeing Annie too, helping the couple pay bills and manage schedules and cleaning. Annie's coordinator, Jamie Crawford, recently left for a similar job outside Wildwood, with a more stable schedule.

Rich pulls a nest of paper squares from a metal tin on the table and begins going over Matt and Annie's weekly receipts.

"What's this from Bed, Bath and Beyond?" he asks.

"Bought a pot. Replaced a pot that was all burned. I guess we could have put water in it and boiled it and cleaned it, but it was too late," Matt says.

"That stuff happens," Annie says. "It could happen to anybody."

"If you're in doubt again, hang onto it," Rich counsels, moving on to balance the couple's checkbook.

Annie watches, but eventually the curiosity is too much. Bills have always been a concern. But then came the months during which Matt was out of work, when he kept worrying about having to dip into savings.

"How we doing?" she asks.

"Looks good. Should cover all the bills," Rich says.

"Our Time Warner bill went up," Matt says. "They don't ever call you to tell you."

"No, Matt," Rich says. "They sure don't."

The year has taught Matt and Annie that not all surprises are bad.

Matt loves his new job. He and Annie commute to work together. They have lunch together, eating the meals they made and packed the night before.

They clean the house together, every Saturday. "I don't like doing it if we don't do it together," Annie says. "As a team, it goes faster."

Now that their schedules are the same, they eat dinner together -- a rarity during Matt's Marriott days. In May, they took a chaperoned trip to Las Vegas, organized through Wildwood.

Things are good. For now, it's back to the little hurdles. It is early evening on a Tuesday in late September. Annie peers over the stove top to see if a pot of water is boiling. She carefully dumps in a sheaf of spaghetti and turns to a package of salami to add to the cream sauce Matt has planned.

She used to be afraid of the kitchen. Not anymore.

"It won't open," she says, prying futilely at the clear plastic edges of the vacuum-sealed package.

"It's all right, Hon," Matt says, pulling out a pair of scissors and moving over to his wife's side.

Annie keeps at it, though, refusing to be bested. Her persistence pays off.

"There you go, Hon," Matt says. "You got it."

Sometimes it's good to have backup, even if you don't need it.

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