

Final Decisions

The Gift: Big Brother Needs a Kidney; I'm His Match

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HOUSTON – I remember being 5, Gary holding me high over his head, balancing me on one palm as I squirmed and shrieked and begged to be put down.

He was the oldest and I was the youngest of nine. Protector and tormentor, this was a game he played. He'd pin me to the floor, practicing the wrestling moves that would make him a state champion and send him off to college on scholarship. Or he'd hoist me into the air, laughing and taunting, "I can hold this position all day." Then, feigning losing his grip, he'd throw me off kilter and "rescue" me just in time to avoid a fall.

Once, he simply placed me on top of the refrigerator and walked away, returning every few minutes to tease, "You can do it. Climb down. Figure it out."

He introduced me to his favorite passion, hunting, by dragging me along at dusk up the creek from our farm to shoot rabbits and then enlisting me as helper – the horrified kid who has to hold the still-warm bunny as the real hunter guts and cleans it.

"If you do a good job," he'd joke, "tomorrow I'll let you vacuum out my car."

He took me on my first thrilling, terrifying motorcycle ride, weaving from side to side on the dusty gravel roads outside Atwood, Kan., our hometown of 1,200. And he took me on my first roller coaster ride, coaching me to scream on the drops to purge my fears.

None of this, of course, could ever have prepared me for the last screaming roller coaster ride we took together as grown-ups: On Oct. 4, 1993, I gave my big brother a kidney.

The decision to do so came easy. He needed it; I had it.

Four of my eight brothers and sisters and numerous aunts, uncles and cousins had inherited polycystic kidney disease, which killed my grandmother before I was born and my dad when I was young. A chance to fight back was handed me.

But in a cruel genetic joke, my kidney also was the only match in my family for another patient – my sister Sherri.

How could I decide between them? One might die without it. Both might die if I chose the wrong one and things didn't go well.

I agonized, but as it turned out, the choice was never really mine. The kidney would go to whichever of my siblings was sickest and need it the soonest.

Being older, Gary's health failed first. His blood pressure shot out of control, infection after infection ate away at his kidney function, and he was often in extreme pain.

Anemia exhausted him, but leg cramps and constant cold sweats stole his sleep most nights. He developed a routine: sleep a couple of hours until he awoke in a soaked bed, change the sheets, shower, sleep, wake, shower, sleep, wake.

Then one day in the summer of 1991, during his regular checkup, his doctor noticed he was rolling his head around when he talked and his speech was slurred – a sure sign that the toxins in his blood were winning against his weakened kidneys.

The next morning, he started the grueling routine of dialysis. Three days a week, he was on the road by 4 a.m. to make the nearly two-hour drive from his home to the dialysis center. By 6 a.m., technicians were sticking him with needles and hooking him up to the machine that filtered his blood. After several hours, he was back in the car, struggling to stay awake for the drive home, collapsing in bed as soon as he got there.

On his off days, he tried to keep up, running his own business building custom furniture.

After a few months, it was obvious a transplant was his only real hope for a normal life with his wife and young son. He started carrying a beeper so the transplant hospital could contact him if a donor were found. Meanwhile, he and I had been through every embarrassing, painful test doctors could think of to satisfy themselves that my kidneys were disease-free and that Gary was sick enough to require the transplant yet healthy enough to survive it.

We were almost ready to go when we ran into a wall. I was at work when the call came: A routine blood test showed I was severely anemic, ruling me out as Gary's donor.

Tears poured as I begged the transplant coordinator to change her mind. Gary and his family were counting on this, I told her, and I had no intention of backing out. She told me to hang up the phone and get myself to a doctor. She wasn't kidding.

Within a month, I had surgery to remove a tumor, which was benign. A year later, we started the transplant testing from scratch. More than two years after Gary started dialysis, I finally gave him that kidney.

My family has been a huge beneficiary of the current system of organ allocation. My sister Marie received a kidney six years ago from a generous family who saw through their grief and offered their loved one's organs for transplant. Their decision and her surgeon's skill yanked her back from the edge of death. Her transplant allowed her to care for her three children after her husband died suddenly and later, to remarry and start a whole new life.

My aunt and two uncles lived years longer than my dad, thanks to kidney transplants.

Gary lives on, riding his motorcycle, coaching his son's baseball team, hunting, working. He has no pain, and at 46, he is determined to grow old with his new kidney.

For a long time, my mind struggled to reconstruct the day of the transplant. Four years later, with the scar fading and Gary healthy, I rarely think about it.

This is what I think about now: as my sister Sherri's health continues to deteriorate, who will decide whether she gets a kidney? How will they choose between her and others who are younger or richer or more famous? Will my brother Greg even make the waiting list? Will my sister Marie, now fighting to keep her transplanted kidney, get a second transplant when this kidney fails?

I want to believe the system is fair, but I can't help wondering, could a movie star or sports legend or politician pull strings that my middle-class, nobody-special family member can't reach?

And when I die and give my organs to help another family like mine, will those people get what I give them? Or will my organs be wasted?

Who really makes the rules that say this kidney will go here and that liver will go there? Doctors? Hospitals? Insurance companies?

These are the questions I have and the worries I share with countless others who will be asked one day – maybe on the worst day of their lives – to decide, yes or no, will you give your loved one's organs, bones, skin and eyes to help someone else?

Because of my experience, my answer would be yes. But for many others, the decision – and someone else's life – may hang on whether they trust the system.

First published in the Houston Chronicle November 30, 1997