

Ashok Rajamani says he is blessed to be alive and functioning from the nightmare of brain injury, that made him want to tell his story

Ashok Rajamani, who survived a brain bleed at 25, tells **Arthur J Pais** how it changed the way he looked at the world

'I try to find humor in the pain of my journey'

The handsome man, around 38 years old, walked into the ladies room and came out in no time before the shrieks started. "Oh, I did it," he muttered as he apologized for his mistake.

Can you really blame him? Ashok Rajamani, survivor of a full-throttle brain bleed at the age of twenty-five, could only see the words MEN outside the WOMENS toilet because the hemorrhage had left him with lifelong bisected blindness, epilepsy, in addition to distorted hearing, erratic transient amnesia, metal staples in his brain, and ultimately, a carved skull because of open brain surgery.

The Day My Brain Exploded: A True Story — a confessional book — full of raw stories and dark humor, is the consequence of his body's very own 9/11, says Ashok.

It is also the story of an immigrant family and its two America born sons, and the racism they had to face in an all white school near Chicago. The book has received praise and media attention for the first-time author who has lived in New York City for over 17 years.

He graduated from New York University in journalism and attended Columbia University for advanced cultural

studies.

Now a brain injury rights advocate, Rajamani has been a regular host for Brain Injury Radio and is a board member of the International Brain Injury Survivors Network, as well as a subject matter expert for the Brain Injury Association of America.

Your book is titled *The Day My Brain Exploded*. Tell us about that day.

The actual bleed that provoked the explosion that day, was, shall we say, something not suitable for children to hear; you'll have to read the book to find out!

The hemorrhage was caused by the explosion of a hidden birth defect called an arteriovenous malformation — a congenital birth defect — that is hard for doctors to detect until it explodes, as was my case.

An AVM can exist anywhere in the body, but is most frequently detected in the brain. Mine had nestled in my brain from birth, awaiting its explosion.

In other words, my AVM was a ticking time bomb. Perhaps most shocking: the event took place in the most surprising of situations — my brother's wedding.

Was this the original title of the book?

The original title was actually *Brain Karma*, but after some thought, my editor and I realized we wanted something more in your face. *Brain Karma*, we felt, sounded more like a book of brain puzzles, or even a book of yoga

instructions.

The title *The Day My Brain Exploded* is colorful, blunt, and vivid, and perfectly mirrors my no-holds-barred writing style.

Your mother felt you were too young to write such a memoir; what was your answer?

I told her, quite simply: "I've died already. I think that's more than old enough."

Why did you choose to tell your story?

There are not enough memoirs by brain-surgery and brain-injury survivors. In many cases, these survivors have become too mentally challenged or face other severe handicaps.

Plus, they are often killed by their injuries. I once asked my brother, "How come there aren't many 'brain injury pride parades in contrast to parades with survivors from other health conditions?" He told me, deadpan, "That's because the marchers are either too damaged to walk, or, they're dead."

I've been blessed to be alive and functioning from the horrendous nightmare of brain injury. I have to tell my story.

I also haven't found enough memoirs by Indian Americans dealing with the issue of race. Americans of Indian and South Asian descent must contend with as

'You mean your God is metal? That's dumb'

Although I was, of course, aware of my somewhat different appearance, I was raised to be proud of who I was as well as of my cultural heritage, something that occasionally created a bit of tension in the environment.

I had to go to Avon Center School, Not too painful. The main problem was my name. Realistically, "Ashok" is only two syllables; it shouldn't be a problem. But on the first day of every school year, the teacher found a new, more inventive way to fuck up my name.

Some variations included Uh-Sheek, Ah-Shook, Ass-hock. Even my classmates were sick of it. With a collective yell at the teacher on the first day of the school year, they would clarify: "It's UH-SHOK!"

The new teacher, flushed with embarrassment, would then say it correctly. By the next day, though, it would be forgotten and we would start all over.

In first grade, our teacher was a Latina named Mrs Marquez. The kids tried to depict her in their Christmas cards. As they did, one after the other called out. "She's not our color!" They held up the peach-colored crayons, which the box had conveniently labeled as "Flesh."

"We can't use the flesh color to draw her," they exclaimed. So they used the black crayon from their boxes.

The statue I was bringing to school was of Lord Krishna as the Vishwaroopa, his multi-headed, twenty-armed avatar, representing God as the ultimate power that controlled the creation, preservation and the destruction of existence itself.

Of course, I did not know how to articulate all that at the age of ten, so Mom explained to me in understandable terms.

"Why does he look like that, Mom?" I asked the day earlier, confused by Krishna's multi-limbed appearance.

"All of his arms and heads equal all the people in the world," she said. "It means God is everywhere."

"So is that the statue of God?"

"Not exactly," she said with a chuckle. "It just shows what God means. But it's still holy."

Mrs Swenton, a fifty-year-old white

The Day My Brain Exploded

Ashok Rajamani

woman who excelled in frumpiness, introduced me.

"Ashok is next," she said, her needle-thin, unpainted lips in action, "to show what he brought. Everyone pay attention."

Just before me, a boy showed us his pet puppy, a golden retriever named Demon. The class, of course, loved the presentation, their "oohs" and "aahs," flooding the small yellow-tiled room. It was a tough act to follow.

I went to the front, gussied up in my au courant gray turtleneck and plaid pants chosen by Mom.

"Everyone," I said, "this is Lord Krishna."

The kids, still panting over Demon, shut up and listened. They all seemed intrigued.

I had my speech prepared. "He's God and this..."

Before I could continue, Leslie interrupted, her blonde pigtails bouncing. "Ewww! You mean your God is metal? That's dumb!"

"Jesus is a man," said Mike, who looked like a sweet, cute version of Curly from *The Three Stooges*.

"You should love Jesus!" some other classmates boomed.

"How stupid," Leslie snickered. "How can God be for show-and-tell?"

"Here is what's stupid," I said. "You think your Jesus is great. I've seen his pictures. He has only two arms. My God has so many arms he can kick your stupid God's butt!"

I had unlocked the door to an invisible sports stadium. Three of the kids, as though rooting for one of the teams in a football game, started cheering, "Jesus! Jesus! Jesus!"

"Krishna! Krishna! Krishna," I countered, trying to yell above the impromptu pop rally. "You know my God can beat up yours!" ■

Excerpted from *The Day My Brain Exploded*, published by Algonquin Books. Copyright, Ashok Rajamani.



I try to find **humor** in the **pain** of my journey

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PANESH GANDHI

much bullying, bigotry, and racism as any other non-white community in our nation. We need such stories that address this fact.

Your resurrection from such extreme brain trauma is quite rare. How would you say you've contended with your survival?

I tell other brain-injury survivors that we shouldn't feel so morose, because I feel we've been given two lives for the price of one. That's how I look at it.

I know I am lucky to have survived well enough to speak, to think, to read, and to write, and to do everything offered in the land of the living.

I try to find humor in the pain of my journey. As I often say, my laughter is far stronger than my tears. When one undergoes a hellish experience, they can either cry or laugh. I chose to laugh.

Tell us about your trauma of dealing with doctors.

Unfortunately, I learned that some in the medical profession have a sordid 'god-complex.' They feel just because they heal your physical ailments, they can belittle your self-worth.

In the book, I mention how a surgeon cruelly dismissed questions about my operation. It was then that I realized a patient's health is only as good as his doctor's humanity. That said, I have also had some wonderful doctors, who have treated me warmly, lovingly, and humanely. I owe much of my recovery to them.

Your memoir details your spirituality. How would you describe your belief system?

I am a proud Hindu. Specifically, I am enraptured by both the aggression and surrender I must ingest to survive. This aggression is symbolized by Shakti, the Goddess Durga.

Surrender is a mindscape created by the loving, passive embrace of Lord Krishna. I survived because of the conflation of the two. This made me rely on a belief in something bigger than myself, a force so great and perfect which would protect me and ensure that I could never be destroyed entirely.

Hinduism is a banyan tree — we can worship God all the way from meditating on God through the path of representative idols and the path of *bhakti*, to the way of *karma yoga*, in which our daily work brings us to the divine, all to the way to *jnana yoga*, a developed view of Vedanta, in which we do not personalize God, but understand in energy and the concept of Brahman, which exists everywhere — an idea that some actually call a form of atheism.

My death and rebirth made me even more a believer of forces beyond control. Whether one calls it 'universe,' 'god,' 'energy,' I know there is something bigger than all of us, as individuals. And each one of us has different paths to discover it. Hinduism maintains, all rivers, all yogas, lead to the same ocean.

The narrative of the book is not chronological. Instead, it slides back and forth between different years and spaces of time. Why did you recount your story this way?

Our thought processes are far from linear. The ways our brain retrieves memories and envelops fresh thoughts are never predictable. I wanted my memoir to conflate both order and disorder, reflecting such mechanics of the brain.

The back and forth motion also forces the reader to be energetic, whereas a chronological narrative does not. Rather, it enforces eventuality: The reader can guess where the timeline of the story is headed, and this can be disinteresting. Many memoirs, unfortunately, take a route as bland as that.

In most memoirs, the writer discusses his or her families. How is yours dealing

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with their compromised privacy due to the book?

Actually, my parents have been totally supportive. South Indian Brahmins so supportive over such raw self-revelation! I was rather surprised.

My mom's late mother was obsessed with the words 'privacy' and 'dignity,' like the Queen of England. She was a devout Brahmin woman who insisted on privacy. I'm sure if she were still with us, she would be wringing my neck, or probably choking me with her sari.

Describe your parents, especially your mother whom you describe as the strongest woman you have ever known.

My mother would come to the hospital, sit on a blue plastic chair, and would be with me all during my days of torture.

I never understood why until I saw the movie *Passion of the Christ* and watched Mary watching her son being crucified, in agony.

I realized that most mothers, no matter what pain their children are going through, will not leave them.

My mother is an incredible woman. She had an arranged marriage and had to learn to be a part of a very quirky family. She then was forced to live in an all-white Midwest town without any Indians, and she was quite the outsider.

But she looked after us very well and gave us a lot of moral support. My father has a very big heart and a great sense of humor, all of which helped me survive the nightmare of my journey.

You write at length about the support you received from your parents. Could you tell us about your brother Prakash and the role he played in the community of supporters?

Like I say in my book, Prakash was my first responder and savior. I couldn't have made this journey without him. He is a lawyer, so practically speaking; his guidance and input were invaluable in any legal matters we had to deal with it, like my medical health insurance.

Emotionally, it was his strength, along with his humor,

which carried me through my journey. Most importantly, throughout my entire life as Ashok 1.0, brain explosion or no brain explosion, he has been my protector, guide, companion, and rival, all rolled into one.

My deep relationship with Prakash is evidenced heavily in the book. The reason is simple: He is my big brother, and whether he knows it or not, we are tied for life, sharing a bond that only two brothers, in our cosmos, could ever share.

Writing this book must have taken a long time. Do you have a 9-5 job? How has your daily living changed since the hemorrhage?

Being a writer is a full time job, but it's not stable, and unfortunately, I don't have a 9-5 job currently to provide such stability.

I volunteer for the brain-injured community as well as write articles, teach English as Second or Other Language to those in need, and hold other odd jobs.

I realized a few years after my brain explosion that it was tremendously difficult to explain my long absence from the work place. Most references I can provide to future employers are over a decade old.

It's so hard to explain the large gap in my resumé now. Sadly, many years ago I had a seizure right in the middle of an interview, which has scarred me entirely. Ever since it has been difficult to effectively seek jobs without certain anxieties.

I now live my life day-to-day. The fateful day I had my brain explosion I had no idea that I would face death when all I did was leave for a wedding.

Also, now that I've been left with epilepsy, I can have fears of having seizures in inopportune moments. This, as well as knowing death can happen at any time... these are issues I never had before the hemorrhage, and now often make me feel that every time I leave my house, it might be for the last time. So the good news is, now I don't leave my apartment messy.

It's like your mother always warns, never leave home with

unclean underwear. You know what? She's absolutely right. You never know if you'll be caught dead in it!

When I had the brain hemorrhage and long hospitalization, to my shock I had discovered my father had cleared out my apartment in Manhattan, and to do that he had to check out everything in it, and take all of my belongings, everything which constituted my life at the time, to his house in New Jersey where I would be staying for a long time.

Naturally, I felt violated. After all, my private life had been torn open. I had arguments with him over that, but later I realized that he had done what he thought was the right thing.

It took me a while to get over my anger, but I forgave him. After all, he is the only Dad I have and I love him dearly. He has been a great support in my journey through recovery.

You write about Ashok 1.0 and Ashok 2.0. Who are these Ashoks?

Ashok 1.0 was a 25 year old more affected by the material world, who basically went for the more visible things — clothes, money and career. He was a heavy drinker, making a lot of money in the public relations world, but not quite living a life rewarding to him.

Ashok 2.0 has been resurrected. He has risen past death, overcome painful surgery, had to fight tremendous amounts of guilt and anger, but he has ultimately been transformed.

He is more spiritual than ever, and he is sharing the concerns of many in the brain-injured community, all the while realizing his main contribution to himself lies not in external successes but within his internal breakthroughs.

What kind of guilt, envy, and anger did you go through soon after your surgery?

Looking at my brother, I would be angry, thinking, why didn't he have a birth defect like me? We were born from the same womb!

At the same time, I was irrationally consumed by guilt of ruining his wedding ceremony by having my brain explode right at that moment.

My mother went through a guilt phase too. She blamed herself for my misfortune, which was the result of a congenital condition.

I told her she should not blame herself but a few months later, it was I who was accusing her for causing the hemorrhage. And yet I knew she was not responsible. She did not drink, she did not do drugs.

I asked her for her forgiveness soon.

Much of my anger and frustration would happen when I would look at myself in the mirror. I looked perfectly normal while knowing that inside me everything had been destroyed.

Coming to terms of my condition helped resolve my anger, and became a big part of my transformation.

As you were recovering from surgery, you gave up two friendships. Why was that?

One friend of many years was a great help to my family and was behind me solidly when I had to go through very complex surgery three months after my bleed. But I came to feel that she had become a Tragedy Queen.

She saw herself as a martyr and I heard her telling a friend that she had to take care of me. I began to feel she was getting off on the fact that I was seriously sick. Her helping me in fact was less about helping me than about her needs, and the need to make her feel important. The friendship has since ended.

Ashok 1.0's closest friend was a brother-figure in every way possible. He was my drinking buddy and we had enjoyed each other's company enormously. We parted ways after my hospitalization though, after it became obvious that our lifestyles were no longer the same.

I've now found kinship and friendship with the Brain Injury Community. We are all wacky and loud. 'Loud' being the operative word! Sure, from time to time I've felt angry and envious of others, but I know now how to handle it.

My friends in the brain-injured community know a lot about these feelings. What surprised me in the hospital was that some of the doctors did not understand how, after losing parts of my brain, I could be uncouth or temperamen-



Ashok Rajamani with his parents Sheila and Puthucode Rajamani. Below, Ashok's older brother Prakash with his daughter Lakshmi

'The tears came gushing like a waterfall'

Arthur J Pais finds out how Ashok's family dealt with the aftermath of his illness

Sheila Rajamani would sit on a plastic chair in a DC hospital and write letters to God in her journal as she watched her 25-year-old son Ashok Rajamani battle for his life.

"Dear God, It has been less than a week since Ashok's in the hospital, nothing makes sense to me," Sheila, who had worked as a kindergarten teacher in a small town in Illinois when her two sons were very young, wrote in March 2000.

Referring to her first born, she added, "We had all come to share in the joy and happiness of Prakash and (his fiancée) Karmen on their wedding day, and Ashok is in ICU fighting for his life. Why did all have to happen at this time? Ashok has just started his new job, and off to a great start. I hope I'm providing him with some solace and comfort, and I hope he knows I'm there in the room."

A few days later she would write to God again. "Please spare his eyes. He's an artist. Spare his eyes. I know God, I am asking a lot from you."

God surely must have listened. Ashok retained half his vision, and a lot of his former life.

She says the most important thing she told her sons while

they were growing up was to be proud of who they were.

"Their experiences growing up were many times quite difficult. But it built in them the resilience to survive, gave them strength of character, made them fearless, emboldened their resolve and enlightened them early on. These qualities have made them the wonderful men they are today, and I am proud of them," she adds.

As Ashok was fighting for confidence and strength after a very difficult surgery, she told him, "There is a reason why you survived. To enjoy the sun, blue skies and a beautiful rainbow, remember not to take things for granted? You've got a second chance for life. Love everything about it."

What kept her going in the hospital and following months? "Keeping a journal, penning my innermost thoughts and

feelings, frustrations and hopes for Ashok, my daily letters to God," she says. "It was a very difficult learning process. No one prepares you in the recovery of a brain-injured person. It is a journey, coping, nursing and dealing with the physical, emotional, mental well-being of a loved one round the clock."

Sheila says when she read the book she couldn't believe how far Ashok had come since "those months restrained in bed in the hospital. I feel pure joy that he is with us, and has triumphed beyond my wildest dreams. The tears that I held back these dozen years came gushing like a waterfall."

Her husband Puthucode Rajamani, who after working for major pharmaceutical companies for over 35 years, has his own pharmaceutical-related business, says Sheila is a woman of extraordinary strength and was a very important player in his son's recovery.

"We were tested all of a sudden and I wonder if there are many families who had to undergo ordeals like us," he says.

He recalls the day Ashok had the brain bleed. His oldest son Prakash rushed in his tuxedo to the hotel suite where he found his brother in great physical agony. "He carried his brother to the nearby hospital, as he did not want to wait for the ambulance as he feared it might take its own sweet time to arrive," Rajamani Senior says. Of course, Prakash or the immediate family did not have an idea what had happened to Ashok.

The hospital people called the insurance and were told that Ashok, who had just started a new job, was not covered. That was a bureaucratic nightmare, as the family had started suspecting the treatment might run into couple of millions of dollars.

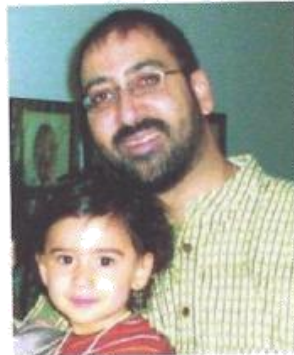
The three Rajamanis had to educate themselves about Ashok's condition, and often they found the doctors not ready to discuss things at length. "Today, I think we have become experts on his health problems," his father says, with a wry laugh.

Though his brother felt several times that he had ruined the wedding ceremony, Prakash says, he himself never felt that way. "We had to do everything we could to help Ashok. He is the only brother I have."

The family was always convinced, he adds, that Ashok had been saved so that he could answer a higher calling and be an inspiration for those afflicted with what might initially seem a hopeless case.

"Many people in his position would have gone into deep depression, a few might have committed suicide," Prakash says. "It is not that Ashok did not have huge problems adjusting to his new reality, and deal with anger and frustrations, but he was able to overcome much of all that because he has a generous heart and an inner life. He

knows he has been saved for a reason and God has plans for him." ■



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tal at times. In fact, there was one doctor who loved to look at me and point 'Inappropriate! Inappropriate!' Looking back, I realized he was in the wrong profession. He should have been a librarian.

Bullying continues across schools in America, and Indian-American students continue to be affected. What are your thoughts today about dealing with school bullying?

Indian-American students are affected, yes. But so are all students perceived as 'different' by their peers — be they be brown, or yellow, or gay, or small, or overweight, or poor, or too-intelligent, or not-intelligent-enough, or black, or Hindu, or

'I try to find humor in the pain of my journey'

Jewish, or Muslim, or anything at all perceived as the 'other.'

Bullying is an acceptable hate-crime in schools, in which the victims are rarely able to fight back.

I was bullied often, be it because of my race, ethnicity, religion, name, intellect, 'wimpiness,' and other issues.

I would like to say I can foresee a cure, but as long as children bully those who are different, there might be no end.

I am hoping we will have more nationwide legislation to help control bullying like the Dignity for All Students Act in New York state. I'm hoping that parents will raise their children by teaching the

virtues of tolerance, and not the fears of difference.

What will your next book be about?

It's going to be fun and frothy: a funny, comical collection of semi-autobiographical stories about the zany, crazy, and eccentric women in my family in India: a sort of Desperate Housewives in Mumbai! There is even a daughter-in-law who falls in love with her mother in law!

The working title of the book is *Adventures in Curd Rice*. For those unaware, Curd Rice is a yummy South Indian dish, containing rice, yogurt, ginger and other spices. I'm very excited about this project. It is more humorous than *The Day My Brain Exploded*. No bleeding brains involved ■