

A terrible accident changed everything,
but it also led to...

SHIVANI GUPTA'S INDOMITABLE ACCESSIBILITY

BY THE EDITORS

SEATED IN HER motorized wheelchair at the round dining table in her small home-office, Shivani Gupta is using her laptop to chat over Skype with a distant client. There are several books in the room and one of them bears her name. It's the 45-year-old Shivani's autobiography, published early last year.

No Looking Back is a poignant, yet often witty, 250-page account of Shivani's struggle for normality after she became a quadriplegic at age 22. She describes how she tries to live life to the full, pursuing a specialization that few in India had explored before, of being rejected in love and finding love once

more. It's also a rare insight into the mind of a disabled person, of the few people around her who can see beyond the handicap. Today, Shivani is an expert on making spaces accessible to all and is helping people like herself.

BACK IN 1992 Shivani had just quit her guest relations job at a Delhi five-star hotel to go abroad for higher studies. She celebrated it with a party. Later that night, she and her boyfriend, Sunil, decided to drop a friend home. Sunil, who was driving, raced for fun against another carload of friends from the party when a tyre burst. The car flipped over, throwing Shivani out.

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Waking up the next day in a hospital bed, Shivani found she couldn't move. Doctors explained that her spinal cord had been damaged.

She lay flat on her back for six weeks with steel supports holding her head in place. Eyes fixed on the ceiling, Shivani wondered about her future, if any. After a former Army surgeon, an expert on spinal injury, operated on her, she was able to use a wheelchair. She even got some movement back in her hands and could now turn her neck. But she would never walk again.

Cut off from friends and with nothing to do, she was lonely and depressed. Visits from Sunil would cheer her up, though she was afraid he'd leave her some day. The simplest of tasks—eating, bathing, or dressing—were a challenge. “Having lost all sensation of pain, I didn't even realize it when I injured myself,” says Shivani. “So I made sure I stayed away from hot or sharp objects. As I learnt to live the life of the disabled, I got little time to reflect on my miseries.” Eventually, Sunil married another girl, leaving her bereft.

After a friend gave her a box of poster colours, Shivani tried to paint. Initially, she could barely pick up a brush. But it felt good when she finally achieved meaningful images. Her paintings, which she folded into cards and mailed to friends, looked good. A friend suggested she make greeting cards to sell at a college fete—a huge first step. “It made me realize that my disability was no excuse to avoid earn-

ing a living,” she recalls. Shivani began exhibiting her paintings and even held a solo show, but she was never sure if people were only buying her works out of pity. Painting never became her profession, but it helped focus her mind and improve the use of her hands.

Though she had a full-time carer, Shivani rarely went out. But when she did, she realized the world had changed for her. People looked at her with pity, openly talking about her bleak future, of how she'd never be able to work or marry. Visiting Haridwar once with her father, she was in the temple queue when a woman came up to them. The next thing she knew, the woman was pressing a 25-paise coin into her hand. “No, no! This is not mine,” Shivani protested, meaning she hadn't dropped the coin. As the woman left without a word, the truth dawned. She laughed it off at first, but that “charitable” gesture had shaken her to the core. Just because you are disabled, people assume you are needy.

ON HER COUNSELLOR'S SUGGESTION

Shivani agreed to train to become a ‘peer counsellor’ at the new Indian Spinal Injuries Centre in New Delhi's Vasant Kunj. “I felt drawn to the work,” she says. “Having suffered the trauma of spinal injury, I knew I could help rehabilitate others like me.”

So, in 1996, Shivani was sent to the UK on a six-week training program. There, she was amazed to find a society that cared so much for the

disabled. She noticed how—unlike in India—wheelchairs didn't stop their users from going out and having a good time. At one party, wheelchair-bound people swayed to music, sang, drank and enjoyed themselves. In the midst of all this fun, a paraplegic young man, Andrew, publicly proposed to Nina, a non-disabled young woman and the pair got engaged, then hugged and kissed each other. *Was all this possible?* Shivani wondered. The trip opened her eyes, teaching her that disability need not be “an end to the road.”

fun-filled office trip to Nainital (as always, a carer accompanied her) she was shattered to learn that the others hadn't really wanted to take her along until Vikas put his foot down and insisted. “My disability outweighed me even in the eyes of my colleagues who worked with me to help other disabled people,” Shivani later wrote.

Yet Shivani could draw wisdom even from a painful revelation like that. “It wasn't something I could blame them for—they had merely reacted in a manner society had taught them to,”



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Back home, she joined the spinal injuries centre, where she was also offered a place to stay. It was very basic, but it saved her the long commute from her father's house. She soon got engrossed in work and found new friends, including the charming and brilliant Vikas, an occupational therapist who was seven years younger than her.

At the centre, the very patients she counselled often inspired her. “I drew courage from people in harder circumstances than mine, disability being irrelevant, who continued to live life no matter what,” says Shivani. But there were realities to face. Her young colleagues often praised her courage and professionalism, but once after a

she explains. She even learnt to “assist” others by letting go happily in case they did not want to include her in some activity and spoil their fun. Such incidents also brought Vikas and Shivani closer and the two were falling in love, although Vikas's folks would not accept a disabled girl for their son.

Another time, when Shivani went with her colleagues to watch the film *Titanic* at a Delhi multiplex, she was seated separately because of the lack of wheelchair accessibility. Shivani later complained. The theatre owner apologized and invited her back to suggest changes, which she did. But they never altered anything. Still, it was to give her direction into an uncharted area.

In mid-2002, Shivani left the spine centre to study for a diploma in architecture at a Faridabad college, although at 32, she was nearly twice as old as her classmates. There were difficulties to endure. She couldn't use her hands to make architectural models, so her dad and her carer helped, following her directions. The only places she could access in her wheelchair were a studio and the computer room. There were no disabled-friendly restrooms and so managing incontinence was another challenge. "Bladder training and not drinking any liquids for

larger flat in New Delhi. By the time she finished her architecture course, Shivani was also honoured with the 2004 Neerja Bhanot Award for exemplary courage, and the National Role Model Award from President Abdul Kalam.

Now she wanted to study further. She applied for a scholarship but failed. So, in 2004, she took a student loan to attend the University of Reading, UK, for a post-graduate program, where she could specialize in "accessibility"—all about creating inclusive environments for disabled people. Vikas,



"I was reminded that love is not about possessing but about letting go."

hours helped me attend my classes," she says. "Despite this there were accidents and on those bad days I had to miss classes and leave for home, where I'd cry helplessly." Her father consoled her. "Beta," he'd say, "what cannot be cured must be endured."

Most of her young classmates, she realized, were from affluent families and wanted to study abroad after the course. By then, Vikas too had resigned from the spine centre and left for a job in the UK.

Meanwhile, Shivani got ₹24 lakh as compensation from the Motor Accident Claims Tribunal for the 1992 car accident. This helped her move into a

already in the UK, joined her as a part-time student.

When she returned, Shivani was offered a senior position at a big New Delhi corporate house. The office building had a VIP entrance with a ramp that was wheelchair accessible, but she wasn't allowed to use it for weeks although, ironically, her job was to set up accessibility programs for the disabled across their offices in India! This and other, more subtle, discriminations she faced regularly at the workplace made her resign after ten months. Yet, she explains, even those negative experiences gave her a deeper understanding of the attitudes that are

important to her field of architecture.

It was now time to work for herself. Vikas returned from the UK and, with another friend, they started AccessAbility, their own company, from the same round dining table in her flat. In months, they got several important clients, which included hotels, supermarkets, universities and hospitals. Among them was ITC. They made every property ITC's hotel division owned more comfortable for disabled and elderly guests. Vikas and Shivani also co-authored two booklets, *Employing Persons With Disabilities* and *A Guide to Universal Design in Built Environments*. These quickly became ready-reckoners in their specialized area. AccessAbility's work also got them two prestigious awards in their field: The Ability Award, and the NCEPDP-Shell-Helen Keller Award.*

IN TIME, VIKAS'S PARENTS accepted Shivani, who discovered a loving, close-knit Punjabi family in his home. He proposed and the two got married in April 2009. Everything seemed as perfect as it could be for Shivani. Vikas's parents, whom she called Mummyji and Papaji, were so fond of her that the newlyweds decided to take them along to Manali for a long weekend. Four months after the wedding, it was their first holiday out as a family.

Vikas was at the wheel on their way

**NCEPDP is short for the National Centre for Promotion of Employment for Disabled People.*

to Manali when an oil tanker hit their car head-on. Shivani and Mummyji survived with injuries. "I can't forget the last time Vikas and I looked into each other's eyes," Shivani writes. "Blood was oozing from his chin and neck." Both Papaji and Vikas were killed following the accident.

For a while, Shivani says, she no longer saw any meaning or purpose in her work, her triumphs or the awards. "I felt that God had pulled me out of a crowd and kicked me hard like a football," she wrote. "I lay in my bed thinking why it was always me having to rediscover myself again and again. Why was I the one who received these wild blows of fate just as I seemed to be getting comfortable in my life?"

But as time passed, Shivani could think more objectively. "I was reminded that love is not about possessing but about letting go." Shivani got back to work, and it's the work itself for disabled people that matters now, not accolades. Loving her work, she says, is her best tribute to Vikas, whose presence she feels everywhere.

Shivani's autobiography ends with a poem. Its last lines are addressed to Vikas:

*And since I know I can't exist without you,
If I exist, then you exist too.*

With reporting by Aditya Sharma and Padmavathi Subramanian. Material has also been adapted from *No Looking Back* (Rupa, 2014), Shivani Gupta's autobiography.

