



## cope as a caregiver

Parents in challenging situations deserve extra support by their peers and families. But they must also learn how to care for themselves. by **RITIKA JAIN**

**“THE OWNER** of a grocery shop in the neighbourhood says, ‘Your son is mad, take him away from here.’ These are the people who know of my son’s condition and are still insensitive, imagine the ones who don’t know that he’s autistic and get offended for simple things like him breaking a queue. I’m forever apologizing and explaining to people. He refuses to go to school, for therapy, and sometimes even to the park. He just wants to eat and watch videos. He’s also not communicating very

clearly so there’s an increasing gap between us. He is 14 now, and doesn’t wear pants at home. He is full of energy and keeping him busy is a big task,” says Amit Khosla from Mumbai, an exhausted but dedicated dad to Ishaan. It’s a tough journey for parents like him. There are many others who didn’t have the good fortune to hear, ‘everything’s okay’ at the birth of their child. They saw varying symptoms as the kid got older.

Nidhi Jain from Chandigarh has had to accompany her son to

school every day because he suffers from a nerve problem that can make him have a seizure and fall anytime. He is otherwise a healthy, cheerful kid. Although every parent qualifies as a caregiver, these people have a completely different sort of life cut out for them. Imagine when it’s a luxury to go to the parlour or a movie, and it’s hard to leave your child in anyone else’s care. Imagine being uncertain and worried about your kid’s future after you’re gone. It can be physically taxing and

psychologically stressful to be in this position. Like they said in the French film *Mommy*, "You think you're invincible, but you're not. Love is not enough." These words chill you to the bone because you know there is truth in it. That is why it becomes very important to learn to cope.

### ➔ seek guidance

If you know the parent of a special child, or are one yourself, it is imperative that you seek professional help from an expert. Dr. Raman Girotra, consultant psychiatrist from Gurgaon says, "Caregivers have to remind themselves that disabilities/special needs could be present from the time of birth or acquired later on in life so they have to accept this situation as a challenge. Rather than getting depressed about their situation, they should look at it as an opportunity to do something that brings cheer to someone else. But at the same time, they must not make it their full time job. Instead they should hire trained helpers and pursue their interests or other competing priorities as well. Many organizations, NGOs or private institutions like Udaan, Astitva, National Institute for the Mentally Handicapped, offer different therapies to patients aimed at bringing individual abilities to light, and to help create new opportunities for them. They also offer support to caregivers in the form of counselling or guidance." He further adds, "Family members should not be ashamed of their child, instead realize that others around them must respect and support his right for dignity and self determination."

### ➔ do not despair

"In reality, it is tough in the social context because others are not

sensitive to your needs and are not mindful of what they say or how they behave. I get depressed sometimes, and my wife and I don't have a regular relationship. I don't think parents usually go very specifically to doctors for their own counselling until and unless it's very serious. They might bring up their own issues also when they go for the kids. These sessions are indeed beneficial, as most of the parents dealing with these kids are going through depression and feel alone, or often sacrifice their own needs in the process. For example, I've been suffering from panic

\* "Family members of a special child should realize that others around them must respect and support his right for dignity and self determination."

—Dr. Raman Girotra, psychiatrist

attacks and anxiety for a very long time. I get scared if a bike comes close to my car while driving, and there are many such fears for no reason. Similarly, my wife is not able to think of small solutions for day-to-day work. These sessions help to understand where we're going wrong and how we can overcome these issues," says Amit. He himself volunteers at various workshops from time to time. There are many support groups created by parents themselves on Facebook. There are also formal groups like Next Generation, Mumbai, created by psychiatrist Dr. Harish Shetty.

## PARENT-SPEAK

A mom shares how she coped during difficult times.

"Priyanka was diagnosed with a defect in the skull bones, when she was just 1.5 years old. She's had surgery for skull shunting twice and has to be on medication indefinitely. She's all grown up now but still needs to be careful. Eight hours of sleep is mandatory for her else she starts getting migraine attacks. I went for counselling a couple of times in the beginning, but what really saw me through was the habit of writing in my journal every day. It helps to spew your pent up emotions on to paper. The support of family is hugely important too."

—Rachna Rampal, Faridabad

Apart from social concerns, there are finances and education to consider. Thankfully, there is a growing acceptance and an effort to promote awareness and empathy in schools, and a number of institutes are absorbing special needs children into their fold. But handling expenses for physiotherapy and with each doctor's visit costing ₹700 and up, there is little room for saving for a middle class family. It can all be very daunting indeed.

### ➔ self care is important

Here are, in a nutshell, what experts advise to ward off depression and anxiety:

1. **Acknowledge your situation** and don't suppress your emotions. Forcibly trying to put a positive spin on things can do more harm than good. Be honest with yourself.
2. **Read up on the condition** you're handling, and don't let any surprises shake you up. There



You will be ready to face the world if you are well rested.

are books available online like *Caregiving: The Spiritual Journey of Love, Loss, and Renewal* by Beth Nitrogen McLeod. Movies like *The Fundamentals of Caring* may cheer you up. Humour can seem unimportant in the context of depression, but it can be a useful way to release tension.

**3. Take care of your own needs.** It cannot be emphasized enough. If you are in a bad state of mind or are unwell, you won't be in a position to take care of another person.

**4. Schedule a half an hour break** for yourself every day so people around you understand this requirement and work around it.

**5. We can't escape guilt** but if you label it as healthy or unhealthy guilt, you'll find ways to manage and even delegate a few responsibilities.

**6. Get organized and follow simple rules** like no TV during dinner time. You'll hear a lot less whining once these rules are established. Planning ahead and time management helps to achieve daily targets.

**7. Don't be imprisoned or isolated** inside your house. Being in touch with other human beings

is crucial to your mental health, as is eating right and exercising. Talk to friends, workmates and family about what you're dealing with, and ask them for their support if necessary.

**8. Indulge in a hobby.** It can be a great stress buster too. I will also assist in developing concentration and patience, which all caregivers need in abundance. Other positive strategies include relaxing through meditation, or listening to music to calm down.

**9. Renew your perspective** by taking a step back. Remove yourself from the situation if it becomes overwhelming. Have a relaxing bath or go for a walk. Write down your thoughts in a journal so they begin to make sense, and go through one day or one task at a time.

**10. Accept what you cannot change.** It takes a lot of courage to accept our lack of control over the lives of people we care about. Fighting against the grain only leads to anger and frustration, and wastes energy. Tell yourself you're doing the best you can. If you ever lose control, remember that nobody's perfect. ●

## FIND HELP

Here is a directory of institutes and clinics across India, where parents can go for counselling.

### DELHI NCR

● **Udaan** (for the disabled)  
Ph: 011/41621137  
[udaan.org](http://udaan.org)

● **VIMHANS**  
Ph: 011/29802980

● **Children First**  
Ph: 011/46084844  
[childrenfirstindia.com](http://childrenfirstindia.com)

● **Dr. Raman Girotra**  
(Consultant Psychiatrist)  
Ph: 0/9818708389

● **Dr. Sanjiv Dang** (Audiologist)  
Ph: 011/4102 6102

### UTTARAKHAND

● **Astitva** (counselling for people subjected to violence)  
[astitvaonline.org](http://astitvaonline.org)

### MUMBAI

● **Next Generation**  
Ph: 0/9820032178

● **DISHA Disability Helpline**  
Toll Free No: 1800-22-1203  
[childraise.com](http://childraise.com)

### SECUNDERABAD

● **National Institute for the Mentally Handicapped**  
Ph: 040/27751741-45  
[nimhindia.gov.in](http://nimhindia.gov.in)

### ANDHRA PRADESH

● **Vijaywada Institute of Mental Health and Neurosciences**  
Ph: 0/8662432040  
[vimhanshospital.org](http://vimhanshospital.org)

### CHENNAI

● **We Can** (autism)  
Ph: 044/42862221  
[wecanindia.org](http://wecanindia.org)