

Journeys Through the Land of Oz: Parents' Top Twenty Strategies for Managing life (and Stress).

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Parenting a child with a disability is an adventure. Each day brings about another challenge and another test that pushes the limits of ones ability to persevere. It is when these trials are overcome and the successes, no matter how small, are accumulated that entire families find the strength that they need to continue. These lives are truly inspiring.

In her book *When the Heart Waits*, Sue Monk Kidd portrays Dorothy's journey in *The Wizard of Oz* as an allegory for overcoming life crises. Until the tornado came, all Dorothy had ever known was her simple life in Kansas with Toto, Aunt Em and Uncle Henry. When the devastating event occurred, Dorothy was catapulted from her familiar surroundings to the often-bewildering Land of Oz.

The remainder of the book was the story of Dorothy's profound longing for her home and her subsequent

wanderings through Oz in order to find it. Dorothy was told that the way home would involve a very long journey, "through a country that is sometimes pleasant and sometimes dark and terrible." Kidd reminds us that at some time in our lives, each of us will encounter a "tornado" experience and, like Dorothy, we may find ourselves in a strange land with no road map and few recognizable landmarks, longing for our former, familiar lives.

Dorothy navigated her way through Oz with the assistance of three new friends she met along the way: a Scarecrow who needed a brain, a Tin Man looking for his heart and a Lion seeking courage. Kidd claims that these characters are sent to remind us that in the midst of any life crisis, what each of us needs for safe navigation "home" is a new way of thinking, a new way of feeling and a resolve to persevere.



For the past several years we have been talking to parents about their journeys in parenting a child with a disability. We began by conducting extensive interviews with 15 parents whose children have a variety of conditions. As they narrated their journey from the initial diagnosis to the present, we asked them to share specific strategies they found effective for managing their personal and family lives. We then developed a survey instrument that we sent to two larger groups of parents. We asked them to indicate how important each of the strategies mentioned by the first group of parents had been to them as they parented their children. In

particular, we were interested in documenting life management strategies that were deemed effective by the large majority of parents, regardless of child age and disability. We have collected information from more than 200 parents. They described how the diagnosis of disability catapulted them into a bewildering new world. They shared the things that both helped and hindered them along the way. And they spoke powerfully of how, through the years, they have developed new ways of thinking, new ways of feeling and a determination to stay the course.

After analyzing these stories, we were able to document a number of strategies that parents held in common. We call these the Top Twenty Strategies for Effective Life Management, and would like to share them with you through the words of parents.

Celebrate your child

"My advice to a parent of a child newly diagnosed is, first of all, just to celebrate the birth of this child. Just to enjoy this child ... because everyone else will try to give him a label." [mother of a nine-year-old son with severe multiple disabilities]

Choose to focus on what's going right

"I dwell so much on the

positive that you would think Ryan was actually pretty high functioning, [though] he's very, very limited in what he can do. But I don't look at those things. I think it's much easier to celebrate the little successes and sometimes they're minuscule. You have to look at the positives and the little successes and dwell on those." [mother of a nine-year-old son with autism]

Get beyond the "why?" to the "how?"

"If we could all just accept our kids and teach them they're pretty great just the way they are ... the sooner you do it the better it is. Pretending like they're gonna get well later--oh, I went through that phase. It was always some miracle that was going to happen. But that's all dead time, all `no growth' time for you and your child. So the sooner you can say, `This is how it is. Let's go forward from here,' the better it is for everyone!" [mother of an adult son with profound hearing impairment]

Appreciate what your child contributes to others

"Last year one of Jana's friends wouldn't go to Brownie camp unless Jana went. This friend's mother phoned me, desperate, weeks before camp: `Jana's not getting sick, is she? She's still going to go, isn't she? Because my daughter will not

go without Jana.' And so we learned that Jana is a support to her friends, she does contribute. And those are the things we needed to start looking at." [mother of a nine-year-old daughter with Down syndrome]



Trust your instincts

"After two years [of preschool] I felt very frustrated. I used to leave there crying, thinking, `Why are you letting them do that to him and treat him like that and talk to him like that?' But slowly I developed the confidence to decide I don't have to be this way any more! Now I think there's nothing that I couldn't do if I set my mind to it." [mother of a nine-year-old son with autism]

Don't go it alone; ask for help

"I needed to take my daughter to another city for treatment and we didn't have the money to pay for the airline tickets. I was moved to phone our minister--I'd never, ever asked for help from this church before, but I

called and explained our situation. They were able to give us some financial help. And the minister phoned down to some families in that city and asked if someone could meet us. So a couple met us at the airport. They put their arms around us and kept them around us six whole weeks. And when we came home I realized that it wasn't Mandy who had had the healing, it was me. And it sort of turned my thinking around; I learned that you don't get help unless you ask for it. As long as people think you're okay, they leave you alone." [mother of a 17-year-old daughter with moderate developmental delay]

Reassess success

"You have to learn to come up with your own definition of what a successful child is, and not bow to the theory that the successful child is going to grow up, get married, have a good job and do this and that. You have to say, 'Well, for our child it will be different. For him success might be something else.' You have to throw out the old definitions. As long as he's happy at what he's doing, why should we define [what] happiness [is]?" [father of an eight-year-old son with pervasive developmental delay]

Utilize planned perseverance

"I spoke with a resource person and she said, 'Every year you're going to have to address the same issues: Who's going to be the teacher? What kind of support is there going to be and will that be sufficient for my child? Every year you're going to have to address this. Just put it on the calendar.'" [mother of a six-year-old son with an undiagnosed genetic condition]

Be a parent first

"There's one thing I'd do differently now. When we found out Jeremy was hearing-impaired, I signed up for a course, 'How to work with your hearing-impaired child.' And all of a sudden I turned into his teacher instead of his mother. But finally, a few years ago, I just woke up and said, 'I'm sorry. I'm not doing this. I'm not going to sit across from the table and force him to do this. I'm just going to practice being his mother.' And I'm much happier. I feel it was like a weight lifted off me." [mother of an 11-year-old son with cerebral palsy and profound hearing impairment]

Keep your sense of humor

"The stories about Nathan have become family tradition. Lots of families have stories that they tell and retell. But the Nathan stories in our family are the funniest--he's

just hilarious. Oh, there have been lots of stressful times. For every funny story there are probably 10 or 20 difficult stories--stories of challenges and trials. But it's the funny stories that keep you going." [mother of an 11-year-old son with Down syndrome]

Be flexible day to day

"Because of her illness, how she feels fluctuates a great deal. So I wrote a list called White Days, Gray Days and Black Days. On 'white days' [the good days] I might go to the park, go out, cook dinner, make the most of a day when Laura's feeling well and has some energy. 'Gray days' [in-between days] I still put things on my list, like cook supper--but it's more like sit and watch a video with Laura, read books, or go to work, as she can still go to the babysitter on gray days. On 'black days' when she's really ill, we might order pizza or, if there are plans, change them." [mother of a seven-year-old daughter with degenerative metabolic disorder]

Give yourself a "time out"

"I have one night a week and it's mine. I need it. I always have something to look forward to and that's what gets me by. I forget about everything for an evening and go out with my girlfriends. I know none of them can relate

to what I go through. They have stress and they have so-called `normal' kids. If they need one night out a week, I probably need three. But, yes, I just go out and try not to worry about it that night, and somehow the next day it doesn't seem that bad."
[mother of seven-year-old triplets with moderate to severe developmental disabilities]

Allow yourself "ups" and "downs"

"Even though I say I have accepted everything that has happened with Jason--yes, I have accepted it. But there are always times when I will hear a song on the radio and all of a sudden it will hit me, `He's never going to hear that exactly like I do.' I will go through the grieving process again, and I will cry. And then away I go and I'm okay. I think this is just a life-long thing. He's going to be my baby even when I'm 80 years old. And I think it's okay to give yourself permission to keep feeling."
[mother of an 11-year-old son with cerebral palsy and profound hearing impairment]

Remember to nurture your marriage

"Court your wife. You know she's going to be stressed out, and so will you, and you will need each other. Do what you need to find time to be with each other. Go to dinner--go

to a movie--do whatever you want to. Find time when you can be away from the demands and just be together." [father of a 12-year-old-daughter with severe developmental delay]

Be a family

"As a parent, you have to set an expectation to make things happen. One thing we do is go to a lodge in the mountains. The whole family goes, and you think, `Yes, we can still do things as a family.' And we've always insisted that we eat breakfast as a family. Sometimes our kids complain, but I think it's important to be together as a family." [mother of a nine-year-old son with severe multiple disabilities]



Balance time together with each of your children

"My son once said, `You really do like Tommy much better than us, don't you?' I asked why, and he said, `You're always spending time with him and you're always holding him.' Well, one thing an experience like this does

to you is to make you think consciously about a lot of things you never thought about before, like spending time with your other children. And I guess it's not being afraid to talk to your kids about the situation, either."
[mother of a nine-year-old son with multiple disabilities]

Know what you want and go for it

"I think the ability to problem-solve is very valuable. Don't take `no' as a final answer; take it as a definite `maybe' and go from there. A lot of times they say `no' because they think you're going to go away. What you need to do is try to analyze the situation. If you do your homework, are well prepared, and make a legitimate argument, oftentimes people will listen." [mother of a 25-year-old son with Coffin-Lowry syndrome]

Be resourceful; find ways to be understood

"A neighbor came in one morning and we spent a morning taping Rachel in spasm, just to show the work that was involved in caring for her. We did it for the medical profession, because they couldn't understand my story. So I have it on video. I have shown it to social workers, too, and I think it would be a good tool for group homes so they can be prepared for the kind of help

needed." [mother of a 17-year-old daughter with moderate developmental delay]

Connect with other parents

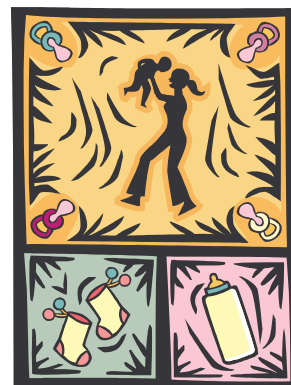
"I feel it is extremely important that parents of children with disabilities make contact with each other, because there's nothing like speaking with somebody who's in the same boat. There's something that draws us all together. If I'm having difficulty with something, I will not call the professionals. Other parents are the first people that I will call. I will ask another parent, 'Did you have to deal with this? How did you handle it?'" [mother of 11-year old son with cerebral palsy and profound hearing impairment]

Value the journey

"When I look back I realize my son has been a wonderful teacher to me. He's had an impact on so many lives-- that's the wonderful part. When Chris was young I used to think I had to know [right now] everything he'd need to know. In time I learned that as Chris grows, I will grow. And I will have the knowledge needed to meet his challenges. It was very important for me to recognize that." [mother of a 15 year-old boy with Down's Syndrome]

These are twenty of the life-management strategies most often mentioned by parents in our studies. Every family that participated in our study was diverse, complex and unique, and each employed the

strategies in a way that was unique to their family situation. It seems that there are many paths through the Land of Oz, and through working together parents can create useful roadmaps and identify familiar landmarks.



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