

# ***When the Caregivers Need Healing***

**By CATHERINE SAINT LOUIS**

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“This has happened before,” she tells herself. “It’s nowhere near as bad as before, and it will pass.” Robbie Pinter’s 21-year-old son, Nicholas, is upset again. He yells. He obsesses about something that can’t be changed. Even good news may throw him off.

So Dr. Pinter breathes deeply, as she was taught, focusing on each intake and release. She talks herself through the crisis, reminding herself that this is how Nicholas copes with his [autism](#)<sup>1</sup> and [bipolar disorder](#)<sup>2</sup>.

With these simple techniques, Dr. Pinter, who teaches English at Belmont University in Nashville, blunts the stress of parenting a child with severe developmental disabilities. Dr. Pinter, who said she descends from “a long line of the most nervous women,” credits her mindfulness practice with giving her the tools to cope with whatever might come her way. “It is very powerful,” she said.

All parents endure stress, but [studies show](#)<sup>3</sup> that parents of children with developmental disabilities, like autism, experience [depression](#)<sup>4</sup> and anxiety far more often. Struggling to obtain crucial support services, the financial strain of paying for various therapies, the relentless worry over everything from wandering to the future — all of it can be overwhelming.

“The toll stress-wise is just enormous, and we know that we don’t do a really great job of helping parents cope with it,” said Dr. Fred R. Volkmar, the director of Child Study Center at Yale University School of Medicine. “Having a child that has a disability, it’s all-encompassing,” he added. “You could see how people would lose themselves.”

But a study published last week in the journal *Pediatrics* offers hope. It found that just [six weeks of training](#)<sup>5</sup> in simple techniques led to significant reductions in stress, depression and anxiety among these parents.

Researchers at Vanderbilt University randomly assigned 243 mothers of children with developmental disabilities, genetic syndromes or psychiatric issues to mindfulness training or “positive adult development.” At the start of the study, 85 percent of the participants reported significantly elevated stress; 48 percent said they were clinically depressed, and 41 percent reported anxiety disorders.

The first group practiced meditation, breathing exercises, and qigong practices to hone mental focus. The second received instructions on curbing negative thoughts, practicing

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<sup>1</sup><http://health.nytimes.com/health/guides/disease/autism/overview.html?inline=nyt-classifier>

<sup>2</sup> <http://health.nytimes.com/health/guides/disease/bipolar-disorder/overview.html?inline=nyt-classifier>

<sup>3</sup> <http://www.ncbi.nlm.nih.gov/pubmed/20592593>

<sup>4</sup><http://health.nytimes.com/health/guides/symptoms/depression/overview.html?inline=nyt-classifier>

<sup>5</sup> <http://www.ncbi.nlm.nih.gov/pubmed/?term=miodrag+autism>

gratitude and reclaiming an aspect of adult life. Both groups were led by specially trained mentors, themselves the parents of special-needs children.

The parents were assigned some unlikely homework: In the mindfulness group, for instance, they were told to bring a moment-to-moment awareness to a daily activity like chopping vegetables. An assignment in the positive development group might entail taking a “guilt inventory” to assess if your guilt is healthy or counterproductive.

Part of what makes the experiment innovative is that it was targeted to adults, not their children, and it was not focused on sharpening parenting skills. Instead, parents learned ways to tackle their distress as problems arise. The idea is to stop [wasting](#)<sup>6</sup> energy resisting the way life is.

The mindfulness treatment and positive adult development led to significant reductions in stress, anxiety, depression as well as improved sleep and life satisfaction among participants. But the mothers in the mindfulness group saw greater improvements in anxiety, depression and [insomnia](#)<sup>7</sup> than those who receive positive adult development training. (As there was no control group, it’s hard to know how many parents might have improved on their own.)

Stress-reduction groups like these could be a cost-effective way for parents to help other parents, Dr. Volkmar said: “We could think about doing this more broadly to reduce stress and improve quality of life” — for siblings, too.

In August, [manuals detailing the two strategies](#)<sup>8</sup> — mindfulness and positive adult development — will be available online for \$200 each (\$350 for both manuals) for parents of special-needs children who want to start groups.

Learning to quell distress and anxiety is especially important for parents of children with development disabilities because it’s often a lifetime caregiving commitment, said Elisabeth M. Dykens, the lead author of the Vanderbilt study.

“Other 21-year-olds move out and take jobs, but most of these children stay at home,” said Dr. Dykens, the director of the Vanderbilt Kennedy Center. “You have aging parents and aging offspring. You are each other’s for life.”

Still, just as some middle-aged caregivers of elderly parents are reluctant to shift the focus to themselves, so are some parents of special-needs children. The Lexington Center in Fulton County, N.Y., is already using the positive adult development curriculum, after two people involved with the Vanderbilt research trained seven mentors last November. But to persuade parents to attend, the center has had vigorously advertise, call and email.

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<sup>6</sup> <http://health.nytimes.com/health/guides/symptoms/muscle-atrophy/overview.html?inline=nyt-classifier>

<sup>7</sup> <http://health.nytimes.com/health/guides/specialtopic/insomnia-concerns/overview.html?inline=nyt-classifier>

<sup>8</sup> <http://vueinnovations.com/psip>

“They are so stressed to begin with,” said Nancy DeSando, the director of community supports at the center. “To get them to consider one more thing is very challenging.”

Karen Pilkerton, a [registered nurse](#)<sup>9</sup> and a peer mentor who led mindfulness training at Vanderbilt, said participants tended to think, “I don’t have time for self-care.” By the end of the six weeks, she said, they realized, “ ‘When I fill my own cup, I have more to give.’ Sometimes, they didn’t realize how depleted their cup was.”

Indeed, [one 2008 study](#)<sup>10</sup> by psychologists at Swansea University in Wales noted that high levels of parent stress reduced the effectiveness of interventions for the child.

Phil Reed, a psychologist at Swansea and author of the coming book, “Interventions for Autism, said, “It’s good that people are beginning to look at how we can help parents in and of themselves.”

Janet Shouse, a mother of three including a son on the autism spectrum, led positive adult development groups for the study. One lesson entailed parents allowing themselves to grieve for the dreams they’d once had for their child — but then to limit the time they dwell on that loss.

Another lesson Mrs. Shouse had to learn herself: how to redirect anxiety into positive action. She spent years panicking that she wasn’t doing enough to get her son Evan, now 18, to learn to talk by age 5, or 7, or 10. (She had been told if he didn’t converse by a certain age, he never would, but the deadline kept changing). The first and last time he asked for food, he wanted an apple. She was thrilled.

“It wasn’t until that apple incident, I finally realized, if he’s not able to communicate more adequately, I’m O.K. with that,” Mrs. Shouse said. “It was such a huge relief that I wasn’t striving to do all this therapy and to make every moment a teaching moment.”

During the sessions Mrs. Shouse led, she tried to help other mothers understand it’s O.K. to “enjoy their kids as kids” and to not make “all moments edifying.”

In retrospect, Dr. Pinter said, it’s easy to see how stressed she’d become caring for Nicholas, who just got a job at a church farmer’s market on Sundays. She ground her teeth and chewed ice. At restaurants, she used to crinkle paper straw covers compulsively, but not when her son was at camp. “When we picked him up, I’d start back up again,” she said.

Practicing mindfulness has helped her live more in the moment. “So many people think it’s just out there or ‘I can do it on my own’ or ‘All I need is more money,’” she said. “They don’t know how much it can help.”

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<sup>9</sup>[http://topics.nytimes.com/top/news/health/diseasesconditionsandhealthtopics/nursing\\_and\\_nurses/index.html?inline=nyt-classifier](http://topics.nytimes.com/top/news/health/diseasesconditionsandhealthtopics/nursing_and_nurses/index.html?inline=nyt-classifier)

<sup>10</sup><http://www.ncbi.nlm.nih.gov/pubmed/?term=osborne+parent+interventions+swansea>