



# Recovering from Post-Pandemic Trepidation

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During the COVID-19 lockdowns, it became apparent from conversations, news coverage and social media that almost everyone was struggling with the stress of life and with freedoms being taken away. Uncertainty about the future weighed heavily, and it lasted far longer than we could have imagined. This brought about a new normal, which then took our stress to the *next* level. The question now is *how do we emerge from lockdown and reintegrate into life outside of our homes*.

For autistic people, and their families, the stresses of lockdown were compounded by the isolation. Much of the school experience of those with autism incorporates accommodations and supports that cannot be duplicated via remote means. In addition, education in brick-and-mortar schools goes beyond cognitive learning to focus on improving socialization and communication, both of which must be addressed in autistic individuals. Such socialization cannot be effectively achieved when one is in isolation. In many cases, lockdown caused stagnation of progress, and even regression.

While moving back to in-school learning and away from home-based work environments is cause for celebration, such moves are also cause for more anxiety in many individuals. Besides concerns about reacclimating and rebuilding sensory tolerance, skills, stamina and appropriate behaviors, there are also the ever-present concerns about increased exposure to contracting COVID-19.

An added complication during lockdown was the loss of jobs and livelihoods, especially for an autistic population that is already disproportionately unemployed or underemployed. Getting and keeping a job is difficult enough, but now there is the added stress of readjusting to new norms. The constant change is overloading people, whether they are autistic or not.

My autistic young-adult son David and I were honored to be invited by AAPC Publishing to contribute a chapter to a unique body of work entitled *Life After Lockdown: Resetting Perceptions of Autism*. Initially, this book was meant to be a guide for reacclimation to post-pandemic life in the community, in schools, and at work. However, it became much more than that. Stories of unique experiences emerged, in addition to the expected advice. The sharing ranged from practical advice to deeply personal; in effect, it was a merging of minds and hearts. Every contributor's life is linked to autism in one way or another, either by training, work, or lived experience. As a result, every perspective was addressed. Readers will relate to the writers and gain support, motivation, and tools to keep moving forward.

# David's Lockdown Experience

My son's contribution is particularly insightful as he shared professional and personal experiences that many neurotypical individuals would not consider. It offers new perspectives and understanding of autistic needs. Minimally verbal at age three and the product of special-education schooling until eighth grade, David is now a master's-prepared middle school teacher, as well as a national speaker and author. He moved out of our family home mid-pandemic to pursue his dream of living independently. Let me share some of the content from our chapter in the *Life After Lockdown* book.

Although everyone felt the isolation of social events being stripped away, it was a bigger issue for David and likely for other autistic people as well. He spent a third of his life in therapies learning how to break free from the narrow confines of isolation and life from behind a keyboard. He ultimately transcended the discomfort of socializing and learned how to **converse with** people rather than talking **at** them. In fact, he actually came to enjoy getting out in the world and interacting face-to-face with new acquaintances and colleagues. After all that hard work, he was abruptly sent back to his computer with the potential loss of all that he had achieved.



It was a devastating blow for David, and not simply due to boredom or a lack of a social life. The real fear was that his years of work would be for naught and that he would regress in his skills and comfort level. This extended to his angst about losing the headway he had made in his professional relationships and the well-earned respect he had gained for his contributions. Would he remember how to work with his team? Would resumed anxiety hamper his effectiveness in the classroom? Would he have to start over again at 28 years of age? These were very real concerns that were compounded every month that went by in lockdown. These were worries that David verbalized months before reintegration concerns began arising in the media among neurotypicals. Imagine the magnification of the challenge for people with autism! If society in general was anxious, consider the level of concern experienced by specific groups that already struggled with anxiety and aversion to change.

Besides the increase in David's apprehension, his main "balancer" was also taken away. Theatre is David's passion and therapy, whether he is acting or in the audience. It also provided treasured social opportunities. But the theatre was shut down, along with the relief and escape from stress it provided. The negatives snowballed for months until creative minds brought some ray of hope with virtual theatrical experiences. That is when the old David began to return to us.

When it became apparent that COVID-19 constraints would be prolonged, we searched for *something* David could focus on besides his job. His life was all work and no play. That is when the issue of moving out resurfaced. We had prepared him for this milestone for months but delayed the actual planned move when the pandemic hit. With regression in his mood and with time to spare from cancellation of life outside of work, we jointly decided to use the opportunity to David's advantage. He would have the time to adjust to domestic responsibilities on top of teaching responsibilities, and he would have something exciting to focus on and feel good about. The ultimate outcome was what we had hoped for, but only after a steep learning curve and some negative setbacks. Despite our joy and pride that David weathered the storm and is now thriving with very minimal outside support, the move presented an unanticipated sensory problem.

The problem was that David not only loved hugs for the sentiment they conveyed, but he also physically **needed** hugs for the deep sensory pressure they provided. Firm compression, especially around his chest, relieved the anxiety and inner sensations caused by his autism and Tourette's. After moving out, however, David was no longer in our inner circle. Until my husband and I were vaccinated, we needed to mask and maintain social distance when visiting with David due to our ages and job risks. This meant we could not hug for months. Thus, another "balancer" was taken away from him, compounding his isolation and physical discomfort. He incorporated a weighted vest and squeeze balls into his daily life, but nothing compared to a loving embrace that was therapeutic on so many levels.

David's fear of sensory regression was very real. It took years for him to gradually desensitize to excessive noise and stimulation, as well as to build up his tolerance for his increasingly busy life. He transitioned in steps to the hectic environment of the dynamic classroom experience. Once everything shut down, David worried about how he would respond to all these demands and sensory elements when they resumed simultaneously. At the moment of truth, however, he thought he could handle the returning stimulation just as he had pre-pandemic. A resulting panic attack proved that this was not the case.

# David's Advice

David's main advice to fellow autistic people is to not assume that they can step back into "life" full throttle without a period of rebuilding their tolerance. From his own experience, he recommends using the following steps to accomplish that goal.

- Reestablish past strategies to accommodate renewed sensory bombardment, such as the use of headphones, ear plugs or fidget toys, even if you don't think you need to.
- Build up activities gradually to prevent becoming distressed.
- Make lists to organize and prioritize tasks. This keeps them manageable, and prevents you from forgetting things or feeling overwhelmed. If you write them down and make a schedule, you can see that you have the time needed to get it all done. Make sure you follow through by sticking to your plan. The list alone is not enough!
- Include physical activity in the day and take short breaks to help you focus and work off tension. Such activities as taking the stairs or pacing can help.
- Conclude each school day or workday with an enjoyable downtime activity when arriving home to reset your sensory baseline and recharge for a productive evening. You could even take a brief nap.

The strain on mental health is apparent in society. In my own work, I see increased angst in college students compared to pre-COVID levels, and several of them have expressed it openly. I've noticed unpreparedness and evidence of being overwhelmed in many students. Freshmen had transitioning needs over and above the usual adjustment needed for college because of an unusual high school senior year. All this is magnified in our program, which is dedicated to supporting students with learning differences, some of whom have autism. In my opinion, it has never been more important to offer extensive orientations, or reorientations, or to provide opportunities for students to express concerns or challenges. We have made every effort to help students with executive functioning and study skills, and to provide coaching or counseling to meet their needs.

Aside from the pandemic, life with autism presents many unique challenges. By sharing our own experiences, David and I may be able to help you at whatever stage you and your children are at. We have co-authored the award-winning book, *Expect a Miracle: Understanding and Living with Autism*. It is written from each of our separate perspectives, and is filled with tips, strategies and lessons learned. Covering the challenges and victories of each developmental stage from toddlerhood through to young adulthood, it addresses topics such as sensory challenges, bullying, transitioning, college preparation and success, and acclimation to the workplace.

David always says that we never stop learning, and that the world is our classroom. Consider tapping into the experience and knowledge of others who have also walked the autism journey from varied perspectives. As David and I have discovered, new ideas can be game-changing!



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