

Being a Good Parent Despite Living With Chronic Pain

By Rebecca Rengo MA, MSW, LCSW, ACSW

Bittersweet memories flood Rachel's thoughts as she flips through a photo album. Recently widowed at 62 and feeling melancholy, she pulls out the thick, dusty binder on a whim. With two wonderful children, thoughts of earlier years elicit both joy and sadness. Flipping through the pages, she sees her kids at different ages riding bikes, swimming, riding a roller coaster. Where was she during all this? She was in bed. The most important goal of her life was to be a good mother, but as Rachel searches the pictures and her memories, she wonders if she met that goal.

Rachel reflects back to her teen years when she was full of dreams, showing horses, and dancing. She wanted to be a teacher. Then one morning she woke up with a locked jaw. Little did she know how life would change—it was a ten year journey to find the diagnosis of Temporomandibular Joint Disease (TMJ). No one knew what it was, and she was told to “calm down.” A few years later, following a run in with a drunk driver, she added cervical spine deterioration to her daily pain assessment, and just when she thought it couldn't get any worse she was diagnosed with breast cancer. Thankfully, she has stayed cancer free, but she was left with even more pain.

Rachel recalls deliberating if she should even have children. She had majored in education, but classrooms were too noisy. So, she changed her focus to library science—libraries are quiet! “If I couldn't work with kids, why did I think I could raise them,” she thought to herself. “I wanted to jump in the pool, race bikes, and all of the things kids love to do, but I was never up to it. I was just a bad mother.”

Parenting is a hard job; parenting with chronic pain is like juggling with one arm. You try to keep all the balls in the air, but you can't. It's easy to feel guilty, especially about physical activities. Rachel was now “should-ing” all over herself. She kept thinking she should have played more, taken more trips, cooked bigger dinners, etc.

What the Experts Say

According to Elizabeth Lombardo, PhD, MS, PT, a clinical psychologist/ physical therapist at Mind-Body-Wellness, Wexford, PA, “Should” is a thinking pattern that parents with chronic pain often have that is not helpful.” Some other thinking patterns, according to Lombardo, are “negative filtering: looking only at the negatives while failing to acknowledge the positives, and all or nothing thinking (e.g. I didn't participate in physical activities so I must have been a terrible mother.) Lombardo adds, “Give yourself a break. You can't do everything, but you can be a great parent... Focus on quality, not quantity, time together.”

Rachel's daughter Jena drops by and lights up when she sees the photo album. Looking at pictures together, Jena reminisces, “I remember when I fell off that bike and you had a band aid already out. You told me I rocked and gave me the confidence to get back on.” Jena searches through the pictures, “We don't have any of us playing chess. Remember, many nights I brought the board to your bed and we played for hours? I don't know how you had the patience; I wish I had it now.”

Jena went on, “One of the best things you taught me was to take care of myself. I know I pouted when you wouldn't run me around, but I also learned that it's important to refuel yourself. I grew up thinking that meditating and having massages on Saturday were what mothers did, and of course, I have your love of reading.”

Andrea Cooper, a parent with chronic pain and an American Pain Foundation Patient Advocate shares, “You really need to take care of yourself in order to take care of your kids. It can seem like you always need to put the kids

first, but that can be robbing Peter to pay Paul. Don't overextend yourself." Lombardo agrees, "Take care of yourself. Get the sleep, nutrition, and exercise you need. This is important for you to teach your children. The airlines have it right. Put your oxygen mask on first. You are no good to your children if you can't breathe." Carole Lieberman, MD, MPH, Beverly Hills psychiatrist and Assistant Clinical Professor of Psychiatry at UCLA states, "Parents in chronic pain need to pursue getting help for their pain, even though this is often frustrating and energy-sapping in itself." Lieberman goes on to explain the importance, "Children feel helpless to 'fix' their parent's pain and yet want desperately to do so." Communication and education are important at every developmental stage. Explain your pain/conditions in language that's age appropriate. Let your children know that it's not their fault." As Cooper shares, "Don't always pull out the pain card, but when it is appropriate use it as an opportunity to help them understand."

Cooper further encourages parents to "Focus on positive outcomes. My kids saw me coping with adversity and making decisions. When I started advocacy work they saw me using my experience to improve the lives of others." Randy, Rachel's son, walks in and sees the pictures. "Do you have any of me cooking? I'm still the best cook of all of my friends." Randy goes on, "The other Moms were always too busy. You were the most fun Mom; you taught me to cook, played board games, and glued model airplanes."

As parents we want the very best for our children. Parenting with chronic pain isn't what we envision. Your life is different because of the chronic pain and so is your children's. Flexibility, good communication, modeling healthy self care, being your own advocate, and focusing on the positives can all be valuable life lessons your children can learn from you. Randy grins, "Mom, because of you, I am a kinder, more caring person. I am sensitive to others with pain and medical conditions, even when they can't be seen." Rachel smiles, she is a good mother and she is so proud.

About the Author: Rebecca Rengo is well-known as an expert in managing chronic pain. She speaks from experience; she has worked in healthcare for more than 26 years and has lived with chronic pain for 35 years. She currently provides pain relief coaching and speaks to healthcare, professional, and other organizations. For more about Rebecca, visit www.beyondchronicpain.com.