

## Why Self-Care is Vital for Parents of Children with Special Needs

**Valuable information and strategies for parents and guardians of children with special needs.**

by Cindy Kaplan

The alarm goes off at 5:30 a.m. I stumble to the kitchen and press the button on the electric tea kettle. I stand there, gazing out the window. I have 30 to 45 minutes before anyone enters my space, before someone needs something, before questions are asked and the rituals and demands of the day begin. Some mornings I sit down on my yoga mat, breathe and practice. Other days, I curl up with the dog on the couch, savoring each sip of tea, or sit down at the computer to check email or Facebook.

There is something almost magical about being awake while everyone else in the house is sleeping. This is my time to make it what I want it to be.

I have three children, ages 16, 13 and 7. My 13-year-old daughter Mira suffered a brain injury during labor and delivery that has left her unable to speak, walk or do almost anything independently. She requires all the things that any child needs and then some. She requires stretching every morning to protect her muscles from tightening, shortening and causing contractures. She needs full assistance to get dressed, get to the toilet, brush her teeth, walk to the table, eat her food, help her communicate, get her into her wheelchair and guide her down the driveway to the school bus. She attends a school for children with special needs, but she also has other therapies after school, such as physical therapy, horseback riding and music therapy.

I am a firm believer in allowing our kids to do as much for themselves as they can, but I will never be able to do that with Mira in the same way. We also don't have the luxury of just calling a neighbor to babysit, as we need someone who can lift and transfer Mira, be willing to change her pull-ups and be prepared to handle a seizure.

The heavy load of all that my daughter demands plus the weight of all that we could and should be doing to support her independence and optimal development is more than we are given hours in the day and requires more bandwidth than I can mentally provide. My two other kids are in completely different worlds. Parenting the three of them often feels like parenting three different families. There are very few moments of "today we are going for a bike ride" or "taking a trip into Boston." I sometimes envy the family that can pull into a parking spot, open the door and expect that the others will unbuckle themselves, get out of the car and walk to a destination.

When you are parenting a child with special needs, the need for self-care is even greater and is twice as challenging as for other parents. The pressures and expectations we put upon ourselves as parents are greater than any human can realistically sustain. When we neglect to care for ourselves, we are at risk of exhaustion, illness, resentment and ultimately not being the parent, spouse or person that our children, our partner or ourselves deserve.

The first time I really understood the concept of self-care was when I was away at a week-long workshop on yoga for the special child, more than 10 years ago. My yoga teacher stated very simply, "We can't give our children what we don't have ourselves." I began to contemplate: How do role model patience when I don't have it myself? How do I pass on the value of self-acceptance and respect if I don't have it myself? How do I teach my children the art of being resilient, of taking care of themselves and having loving relationships if I don't model that myself?

Being away from home at that yoga workshop was a fabulous self-care opportunity for me. I returned home relaxed, calm, present and saw things with more gratitude. My husband, noting the difference, encouraged me to go away and practice yoga again. When I returned from this week, I saw my daughter with a different lens. I no longer saw her as a child I was responsible for shaping and making into the person she may never be, but rather a child with a completely intact soul I wanted to get to know. I noticed then that I move more slowly and felt more engaged with my kids, even if it only lasted a few hours.

To view self-care and limit it to external practices that include exercise, a pedicure, going out with friends, time out with our spouse or reading a book, we are likely to build frustration and resentment when external factors get in the way. Even if a sliver of time can be found, spending money and hiring a sitter to accomplish some of these external self-care practices isn't always easy or possible.

Determined to find a way to extend that feeling, I began to look at ways to make self-care a priority at home. The following practices are applicable to all parents, with or without children who have special needs.

### **Outsource When Possible**

As a parent, we sometimes struggle with the notion that no one else can do for my child the way that I do and because it is so challenging to find a good sitter, it is often easier to do it ourselves. We are afraid of what might happen if we are not there to witness a seizure, a tantrum or an outburst. But we can't do it all.

For the first several years of my daughter's life, I wouldn't dare miss a therapy appointment, and there were several a week. I couldn't imagine someone else taking her to the doctor. One afternoon, while I was with my son at the orthodontist, I realized I would never make it on time getting with my daughter to her doctor appointment. I had a sitter picking up my daughter from school to take her to horseback riding therapy and so asked her to take my daughter to the doctor also.

Allowing another person to do the stretching, to take her to therapies and even the doctor if I can't, gives me the opportunity to simply be her mom, rather than her therapist or teacher. I struggled to let go of my fear of judgment from others and myself for having someone else take on some of her needs.

When we allow a spouse, friend, or sitter (money required) to take on some of the driving, stretching, feeding, play time, or bed time routine, it helps if we can see it from the perspective of what the child is gaining, rather than what we are not doing. The child gains practice in flexibility, as different people work with her in different ways.

My daughter cooperates with a sitter during her stretching routine much better than when I wear the hat of therapist. I believe that if I fill every need for her, I will have nothing left to give to my boys. I also recognize that what my boys see in terms of my enjoyment of parenting or adulthood is what they learn to apply and expect in their own future relationships. Having someone else assist with feeding my daughter allows the rest of us as a family to have a conversation. All of the kids gain an appreciation of the reality that parents have needs too, and so do they.

Outsourcing allows us to be responsive rather than reactive and to connect with our children. Connection is necessary in both fun and happy moments, as well as the down and dirty challenging and tough ones.

### **Ask Kids for Help**

Asking children for help with setting and clearing the table, prepping for dinner, putting things away, caring for pets and being responsible for their homework and things that need to go back and forth to school is another way to help lighten our load. Letting them truly take on those responsibilities is also a great way for them to build confidence and feel like valuable family members. When our kids are struggling or upset, we are more likely able to respond to them in a way that will help versus getting annoyed that they forgot their lunch or that they are complaining about the content of it.

### **Adjusting Expectations**

We often find ourselves parenting the child we want to have instead of parenting the child we have. When we do this, we are so attached to the goals that it prevents us from connecting with our child's soul, and we get stuck in a place of judgment, either looking where we want them to be, or judging them for what they are not. Truly accepting my child for who she is allows me to let go of and adjust some, but not all, of my expectations for her. This allows me to be in the present moment more often with her and not so attached to the outcome.

When my oldest son started riding his bike to school, I required him to text me when he arrived. Many mornings he did and some mornings the text didn't arrive. I know that the school doesn't get great reception and that my son is a teenager, and no matter what his intentions are, he is likely to occasionally forget. One morning, as I was leading a parenting group, I was distracted, as I had not yet received a text. At some point I realized that if something happened, I would likely receive a call from school, the police or my son. If I didn't get the call right away, he would likely get help from a passerby and get to the hospital if necessary. Yes, ideally, I would like to know about it as soon as possible, but I also know that I am much better off letting go of the worry and anxiety on all the days that he gets to school just fine. It was as simple as letting go of the requirement to text me.

## **Expressing Myself Creatively**

Think back to activities you enjoyed before having children. Did you sing while you drove? Did you dance around the house to loud music? Did you enjoy reading a good book or doing an art project? When I am involved in some form of creative expression, I feel whole. Going to a dance class or joining a singing group would be wonderful but we can find ways to stimulate our creativity, even when we are with our kids. Rather than taking care of all the “should do” tasks, see what it is like to have a dance party with your kids. Sing out loud while driving your kids from place to place. Practice yoga while your children can see you. Another wonderful piece of wisdom from my yoga teacher is that there is always enough time to do the things we need to do if we do each of them with intention and presence.

## **Time with Our Other Children**

It took me 12 years before I felt comfortable enough taking our two boys away for a weekend without Mira. There is always a delicate balance between wanting to include Mira in every family trip and wanting to experience some things with our boys that we simply can't do or can't do in the same way if she were with us.

In my head, I can justify that if she has a great weekend filled with people she adores and activities that keep her happy. That is not to say that the couple of times that we ventured out without her are free from feelings at times of wishing she were with us and guilt that she is not. I have learned to hold those feelings together with the feelings of freedom that come with being with two typically developing children. As long as I know and accept that these getaways are made up of both feelings, I can continue to make them happen. I have become better at taking the boys to see plays and movies as I want to go with them and taking Mira may mean that we have to leave early. This has been an enormous act of self-care for me.

## **Breathe**

Taking three to five minutes to focus on breathing can have an enormous impact and is one of the easiest and quickest ways to care for yourself. Most of us come into the world breathing properly and deeply. Around the age of 5, we start breathing less deeply and can even breathe incorrectly. While we can't often change the stressful situations in which we find ourselves, we can change the way we respond.

The first step to changing our response is to bring awareness to our breath and alter it. Breathing exercises bring nourishment to our blood, our nervous system and our immune system. By slowing down our breath, we bring calmness to our brain and our entire being.

Sit in a comfortable position and close your eyes. Allow your inhale and exhale to move through just your nose. As you inhale, either count to three or four, or say to yourself, “I am inhaling.” As you exhale, through your nose, count to four or five, or simply say to yourself, “I am exhaling.” Breath is powerful and you can practice it almost anywhere and any time of day.

## **Trust**

While I believe that many of us want to be calmer, more patient and centered when we parent our children, there are many external and internal forces that get in our way. We need to be proactive and intentional, tuning in to the way we want to parent, what values we wish to pass on to our children, look at what we are doing to make that happen and truly accept our children.

When we can trust that our children will one day eat their vegetables, clean their room because they want to, read with greater ease, find their passion when they discover it rather than us pushing it, know how to get through tough moments without screaming, remember their lunch and show signs of gratitude, we can all relax a bit about their future and their day-to-day actions. We can connect with them soul to soul, reaching out to understand them and support them in ways that allow them to fail, while knowing that they are still whole beings who are loved, supported and can come to us for help.

## **Find Little Moments**

I often ask parents to write down all the things that they can think of that make up their day, including the little things that they don't give much thought to. They list things from reading the paper, getting a cup of coffee on their way to work to making dinner, driving, working and reading a few pages of a book before bed. This goes back to my cup of tea. When I began to look at that as something that nourishes me, it had a comforting effect, and I could look at this simple ritual to give something to myself every day.

## Self Care Tips for Parents of Children with Special Needs

In the moment, when our blood is beginning to boil, when we are about to dish out a silly punishment that we know we will not follow through on, when we take on the parenting challenge of needing to fix a situation, or when our body starts to tense up in preparation of release, be it through yelling or grabbing our child in a way that is not gentle, we need to have strategies that protect both ourselves and our kids. The big picture or change in perspective is hard, if not impossible, to grab hold of when we are in these moments. Below are some concrete ways to take care of yourself, in the moment, so that you can access the bigger picture, as well as an effective response.

\* Remove yourself from the situation and lie down on the ground. You can benefit greatly from taking a time out for yourself. You don't need to respond in the moment unless there is a serious safety risk. Connecting to something bigger than us, the floor, can be grounding. Take a few deep breaths and respond when you are ready.

\* Put on some classical music. An external influence of calming music can help to bring us down from the edge. Play the music during times of the day that you can predict will be challenging. It may have a calming effect on your kids as well.

\* Step outside and look up at the sky. The fresh air can be soothing and looking up at the sky reminds us how big the universe is in which our current moment exists. Allow yourself to see the big picture so you can take this moment and put it in perspective.

\* Practice saying the phrase, "Wow. He is having a hard time right now. He is not giving me a hard time." Or "He is having a problem, not being a problem". So much of our reaction is based on the fact that we take so much of what our children do personally. This phrase immediately keeps our kid and their moment to themselves and allows us to observe. When we observe, we create just enough distance to grab hold of a little compassion so we can help our child through connection.

\* Give yourself permission to table a discussion for a later time, a time when you know you can be more present and level headed than when your fears and projections of your future child are derailing you into making threats that you will later regret. Be sure to let your child know when you will return to the conversation. If it is coming up frequently, it is clearly important to them. Assuring them a time for the discussion, confirms for them that their concern is important (to them) and that you are willing to listen. This does not mean that you need to give in.

\* Light a candle. The sound of striking a match that creates a glow of light is just enough to break the mental chaos and redirect your mind. Look at the candle and take a breath. For me, lighting a candle can instantaneously transform a hectic atmosphere into a sacred one.

\* Wake up 15 minutes earlier to adjust to the morning by yourself. Make yourself a cup of coffee or tea and enjoy it without distractions.

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