



Self-Care for Caregivers

Only when we first help ourselves can we effectively help others. Caring for yourself is one of the most important—and one of the most often forgotten—things you can do as a caregiver. When your needs are taken care of, the person you care for will benefit, too. Today we are going to discuss the risks associated with not taking proper care of yourself and some suggestions for making self-care your priority. Amid COVID 19 concerns, we are all spending more time being caregivers, and self-care is more important than ever.

If you are a baby boomer who has assumed a caregiver role for your parents while simultaneously juggling work and caring for your child diagnosed with PWS, you face an increased risk for depression, chronic illness, and a possible decline in quality of life.

But despite these risks, family caregivers of any age are less likely than non-caregivers to practice preventive healthcare and self-care behavior. Regardless of age, sex, and race and ethnicity, caregivers report problems attending to their own health and well-being while managing caregiving responsibilities. They report:

- Sleep deprivation
- Poor eating habits
- Increased anxiety
- Failure to exercise
- Failure to stay in bed when ill
- Postponement of or failure to make medical appointments for themselves

Family caregivers are also at increased risk for depression and excessive use of alcohol, tobacco, and other drugs. Caregiving can be an emotional roller coaster. On the one hand, caring for your family member demonstrates love and commitment and can be a very rewarding personal experience. On the other hand, exhaustion, worry, inadequate resources, and continuous care demands are enormously stressful. Caregivers are more likely to have a chronic illness than are non-caregivers, namely high cholesterol, high blood pressure, and a tendency to be overweight. Studies show that an estimated 46 percent to 59 percent of caregivers are clinically depressed.

In March of 2018 a research article “High Levels of Caregiver Burden in Prader-Willi syndrome” was published. Caregivers reported that caring for a person with PWS negatively impacted their romantic relationship, ability to work, sleep, and overall mood. The findings of this study highlight the unmet need for support for caregivers, specifically:

- Employment difficulties (88%)
- Less quality sleep (61%)
- More mood disruptions such as anxiety (94%) and depression (77%)
- Increased challenges forming and keeping romantic relationships (89%)

If the PWS diagnosis is still new to your family, take some time and space to process your emotions; you're entitled to them. It's okay to be angry, sad, confused, overwhelmed and to grieve; just don't stay there. Accept your child's diagnosis and then focus your emotions on how strong, unique and amazing your child is. The extra attention and parenting fuel needed to raise a child with PWS means self-care must be your #1 priority.

Self-care can look different for every parent, sibling and caregiver. What's important is that you find what works for you. Below are some suggestions for self-care.

Me Time

We all know that taking time for yourself is the number one recommended self-care tip, and every caregiver knows just how difficult that is. Studies show that as little as 15 minutes a day will improve your affect. It doesn't matter how you spend those 15 minutes if it is meaningful to you. If you need to lock yourself in the bathroom for 15 minutes just to get some alone time, do it. Take a bath, have a cup of coffee alone before anyone else wakes up, a glass of wine after everyone goes to bed-you get the idea.

Move Your Body

Exercise provides a natural endorphin rush and stress release. Finding time to exercise may be challenging, especially with all the gyms and schools closed. Consider changing your mindset from "finding time" to "making time". Exercise is important for everyone, including your loved one with PWS; make it a family activity- ride bikes together, play tag in the backyard, go for a walk or run. If exercise isn't your thing, just moving your body will help- roller-skate, swim, dance, the options are endless. These activities will improve your mood and increase your energy.

Do What You Love

What are the things you enjoy most? What were your passions before you had children? Make a list of the things that bring you joy then schedule time to participate in them-weekly or monthly.

Find Your Tribe

I cannot emphasize enough just how important a support system is for caregivers. Find those people who support you, love you and understand you. Your tribe will be those people who you can cry with, laugh with and will pick you up off the floor when you need it. They may be other caregivers who truly can relate to PWS specific stresses. Facebook has many groups that provide online support to parents of individuals diagnosed with PWS and/or other syndromes. Many state chapters offer support systems and family activities that will give you the opportunity to meet other families and develop relationships.

Proper Nutrition

Eating healthy, nutritious foods are essential for not only your children but for you as well. If you go long periods of time without eating during your waking hours (i.e. greater than 5-6 hours), the body does not function at its best. We may not be able to think clearly as our brain is starved of glucose (aka, carbohydrate). We may also experience fatigue, low energy levels, or headaches. If we are planning to

exercise or our day involves a lot of movement, we may not have the best energy levels to get through it. Food is what gives your cells the energy they need accomplish their tasks. Include a balance of carbohydrates, proteins, and fats throughout the day to help nourish your cells with what they need to help you perform. Having a balance of these three nutrients is what I call the “energy trifecta” – it helps keep blood sugar levels more stable and helps you feel more energized throughout the day.

Food provides important compounds that contribute to the hormones in our body which regulate our mood. Carbohydrates and protein affect our ability to make serotonin, aka the “feel good” hormone. Both macronutrients also contain important vitamins and minerals that affect our neurological system. When our cells and brain are not receiving enough fuel, we can experience irritability or what is commonly referred to as being “hangry! On the opposite end of the spectrum, if they are given too much fuel at one time, we may experience lethargy. Tune into your signals of hunger and fullness as well as how foods make you feel. Use the hunger/fullness scale below to practice identifying your signs of hunger. Avoid getting to a level 1 on the scale and try to stop eating when you are at a 5 or 6.

Meditation

Meditation and reflection looks different for everyone, and for some people, it's just not what they need. And that's OK! There are lots of different apps available for your smart phone that will guide you through the process. You might need to try a few until you find what works for you. As a parent, you are constantly working to help your child, you might feel selfish when you slow down to focus on yourself. Taking time every day to channel your inner peace and refill your cup, will give you the energy to enjoy the rest of your day with the utmost happiness and supportiveness for others. Only by having your own mental clarity, free of self-stress and self-inflicted worries, will you be able to show up to the rest of your life the way you want to.

As they say on airplanes, put your oxygen mask first. Amid the chaos and uncertainty, make yourself a priority. You are worth it.