



# Prader-Willi Family Newsletter

## Fall 2021 Edition



### Developmental Behaviorist's Corner: Caretaking of Self and Family

By Dr. Geeta Grover, M.D.

We now understand that exposure to stressful or traumatic experiences may alter the amount of stress hormones that your/your child's body makes, and this can increase the risk for health and developmental problems.

The good news is that we also have strategies that have been shown to help children and adults calm the stress response. These include things like good nutrition, healthy sleep, spending time in nature, regular exercise, mental health support, mindfulness, and healthy relationships.

As parents and caregivers, you play an important role in helping your children deal with stress. We know that safe, stable, and nurturing environments can prevent the development of poor health outcomes and help children thrive. As your PWS team at CHOC, WE SEE YOU . . . and we see the love and support you give your children as well as the sacrifices that you make every day in order to provide them with the nurturing and support they need. WE APPRECIATE EACH OF YOU, OUR DEVOTED PARENTS AND CAREGIVERS!

Through your love, actions, and support, you can make your children stronger and resilient based on the positive and supportive things that you do at home. You being here and helping your child feel safe is the key to calming how their bodies react to stress.

We are including a handout here with strategies to help improve the health and well-being of everyone in your home.

Be well!

### CHOC Family Recipe Corner

With every issue of our PWS newsletter, we want to share a recipe suggested by one of our Prader-Willi families. Consider sending healthy, low calorie and delicious ideas to Laura Clapper, RD at [Lclapper@choc.org](mailto:Lclapper@choc.org).

#### Cauliflower Fried Rice

Cook Time: 10 min | Total Time: 20 min  
Calories: 128kcal | Carbohydrates: 10g | Protein: 4g | Fat: 8g | Saturated Fat: 1g | Cholesterol: 40mg | Sodium: 795mg | Fiber: 2g | Sugar: 1g



### CHOC Family Recipe Corner (cont.)

#### Cauliflower Fried Rice

Looks and tastes exactly like fried rice, but so much healthier for you! Recipe from the Prader-Willi Recipe page on Pinterest. Added by Princess Pinky.

#### Ingredients (for 4 Servings)

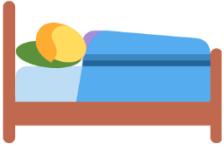
- 1 bag of frozen Trader Joe's Riced Cauliflower, or a head (1 ½ cups) of cauliflower chopped up or "riced" in a food processor. For frozen bag of riced cauliflower, let it thaw for a few minutes and break up the chunks.
- 2 tbsp sesame oil (or canola)
- 1 small onion chopped
- 1 cup of frozen peas and carrots, thawed
- ¼ cup broccoli chopped
- 3 tbsp soy sauce
- Salt and pepper, to taste. Garlic salt is optional.
- 1 egg

#### Directions

1. Heat oil in large skillet on medium-high heat.
2. Sauté onions until tender. Add peas, carrots and broccoli. Cook until tender.
3. Add frozen or fresh cauliflower. Mix with veggies and sauté until no longer frozen.
4. Add soy sauce and mix well.
5. Slide rice to one side of the pan and scramble the egg on the other side.
6. Once egg is cooked, mix in the with the rice and additional soy sauce to taste.
7. Add salt, pepper, and garlic salt to taste.
8. Serve immediately and enjoy!

# WAYS TO TAKE CARE OF YOUR HEALTH

## THINGS YOU CAN DO TO IMPROVE YOUR HEALTH & WELL-BEING



### SLEEP

- Try to get 8 hours of sleep every day.
- Cut down on your use of caffeine, especially in the afternoon.
- Create a “bedtime routine” for yourself and your children.
- Don’t take your phone to bed with you!



### NUTRITION

- Try to eat fresh whole foods from the farmers market or your local grocery store.
- Avoid foods that are very processed or contain a lot of sugar.
- Make sure you drink at least 8 glasses of water a day.



### EXERCISE

- Get at least 30 minutes of gentle exercise every day, including walking, swimming, biking. Walking your pet counts!
- Include weight-bearing exercise in your routine. Both strength and cardiovascular training are important.



### RELATIONSHIPS

- To support your relationships, practice good, honest and open communication.
- Spend quality time focused on those you love. It doesn’t need to be expensive; dinners can be made special with a candle, playtime with a paper airplane.
- Do or say something daily to show appreciation to those you care about.



### MENTAL HEALTH

- Life experiences, biological factors, and family history can affect mental health.
- Early warning signs of mental health issues can include trouble sleeping, pulling away from usual activities, feeling helpless, and unexplained aches and pains.



### MINDFULNESS

- Daily take a few minutes to sit quietly, notice your breath, and feel your feet on the floor.
- When you are angry or upset count to 10 or take 3 deep breaths before you do anything else.



### FINANCIAL STABILITY

- If you can, put money from your paycheck into savings or an emergency fund automatically, before you start spending.
- Set up autopay for bills or pay immediately to avoid late payment and interest fees.



### PARENTING KNOWLEDGE

- Parents are their children’s most important people. Showing love includes having empathy, setting boundaries, and buffering children from toxic stress.



## Social Worker's Corner: Taking Care of the Caretaker

By Bobbi McGann, LCSW

Raising a child with special needs requires a tremendous juggling act. Your days are filled with school activities, as well as attending countless doctor and therapy appointments, as well as dealing with medications and authorizations from insurance companies. What you need is help, but many of you don't ask for it. Or somehow feel you are the only one who can manage all of it.

I am often amazed how well you manage all the needs of your children with PWS. Between work and the multitude of cares required, I am in awe every time I meet with you.

However, I also want to make sure that you take time to care for yourselves. Self-care cannot be considered selfish, yet we all make excuses to not take time for ourselves.

This list is a simple reminder to take a moment for yourself, you need it and deserve it!

- **Accept help from family and friends.** I know many of you believe no one else can get the job done like you can. And I believe this is probably true. And sometimes it is difficult for all of us to ask for help as we see it as a sign of weakness. However, we need to get to a place when asking for help is the norm to those around us. Allowing yourself to be recharged can make you a better parent and a better person. So, if someone is asking to help, say yes!
- **Make a list of what you need and be honest with those around you.** How many times has someone said to you, "let me know if you need anything?" And our response is always, "I will." There might be some people in your lives that are just saying this to be nice, but I bet there are some people who really want to help but don't know how. I encourage you to be specific with what you need. Is it help going to appointments? Maybe helping with drop off at school or sometimes helping with cooking a meal. Giving family and friends specific tasks makes them feel helpful and when you surrender to this help, you realize how wonderful people can be around you.
- **Take time for yourself.** Take breaks daily, even just a few minutes every day. Make time to have time with your spouse for a date night once a month. When you are tired, the last thing you feel like doing is exercise, however sometimes just getting active helps. Take time to go outside and explore nature.
- **Seek support from other parents who have a child with PWS.** Other parents are the true experts of what you are going through. There is nothing more supportive than speaking with another mom or dad who are having the same experiences. We are more than happy to link you to other parents in our clinic.

**Remember, Self-care is not selfish!**



## Dietician's Corner

By Laura Clapper, RD, CDCES

For this newsletter I've compiled a list of food related tips and tricks from a few of our CHOC families. If you have any creative ideas or recipes, please share with Laura at [lclapper@choc.org](mailto:lclapper@choc.org).

### Tips from Allison's mom:

- Always be prepared with snacks and meals when on the go. Avoid stopping for fast food. Once you go to a drive thru, they will ask to go again and again, every time they see one.
- To help your child swallow or chew their meds/supplements, add them to a small paper bowl with fruit (peaches) plain yogurt and a dollop of cool whip and call it dessert
- Or try giving meds with a 70 Kcal strawberry yogurt from Trader Joes
- A yummy breakfast idea is Bakery on Main brand Hot Breakfast quinoa multigrain flakes packets with a little maple syrup. Microwave with water according to directions. (150 kcals)
- Ground turkey with tomato sauce over sweet potatoes instead of pasta. It is okay to serve different food than the family.
- Avoid bread
- Roll ups with turkey
- Don't start offering any new food that you will have to take away later
- Pizza on low carb tortillas with sauce, cheese and veggies (50 kcal per tortilla)

### Eating out tips from Nicholas' mom:

- Talk openly with your child about food security. Having mom close by provides security and the power to resist temptation
- Ask waiter not to serve bread on table, nor chips, nor refills of calorie containing beverages
- Ask for doggy bag when ordering or before the food is delivered to your table

## Something to consider if your child has issues with elopement.

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Jiobit Next is the smallest, longest-lasting real-time location monitor. Keep track of what matters most, no matter the distance. Tiny, durable, and designed for everyday use.

Jiobit requires a monthly subscription data plan to stay connected and includes national US cellular data. No additional SIM card or cellular plan needed.

\*You may cancel your month-to-month subscription anytime. Canceling will terminate the SIM and it cannot be reactivated

Your purchase includes everything you need to connect, charge, and attach your Jiobit right away: The Jiobit Next Location Monitor (with integrated attachment loop), charging dock, USB charger

The first-of-its-kind Jiobit TrustChip delivers unmatched security and encryption, meeting or exceeding US-government standards.



## *Foundation for Prader-Willi Research - 2021 Virtual Family Conference*

The Foundation for Prader-Willi Research (FPWR) had their 2021 Virtual Family Conference from October 5-8<sup>th</sup>. If you weren't able to join, here are links to the YouTube videos.

We have some amazing resources for you! These videos, taken from FPWR's 2021 Family Conference contain valuable information on some of the most pressing issues around PWS: standards of care, sensory integration, managing anxiety, and more. You will definitely want to add these resources to your parenting toolbox! Click on the links below to watch these informative videos on our [FPWR YouTube channel](#).

### **Standards of Care for Children and Adults**

Dr. Jessica Duis provides an overview of general care for people with PWS supplements, genetics, behavior management, therapy, and more about her multidisciplinary approach. [Watch the video for children and adults>>](#)

[Watch the video for infants and toddlers ages 0-2>>](#)

### **Sensory Integration for Children with PWS**

Every child with PWS has significantly decreased awareness. Learn the term AND how you can change the outcomes so your child can thrive! [Watch the video >>](#)

### **Mental Health Challenges in People with PWS**

What do mental health challenges look like in PWS? What are early signs and how can we best intervene? Learn how we can effectively assess & manage mental health issues if they arise in our loved ones with PWS. [Watch the video](#)

[>>](#)

### **Partnering With School for a Successful IEP**

Dr. Katy Chambers is a former school principal, teacher of fifteen years, and mom to Daniel (age 9)- who lives with PWS. In this session, she shares strategies that have been helpful to her as a parent, tips that help school staff better understand



our children's needs, and action plans that help ease the day-to-day stresses of monitoring the safety of our kids in the school setting. [Watch the video >>](#)

### **Strategies for Managing Behavior and Anxiety**

People with PWS struggle with impaired cognition and social development which often lead to challenging behavior. In this session, Dr. Tony Holland discusses strategies for effective management and touches on recent research that shows promise in improving the behavior profile of PWS. [Watch the video >>](#)

### **Feeding Techniques for Children with PWS ages 0-2**

Learn how to develop and advance your child's oral motor feeding skills using video swallow studies, oral motor development, feeding development, and special dietary needs. [Watch the video >>](#)

We hope you enjoy these videos!