



Understanding the PWS Mindset
and
Development of Coping Skills



By Patrice Carroll, LCSW
Edited by Katrina Fryklund, MSPC

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The Beach

by Latham Students

The beach sounds like waves crashing on the sand.
Like seals chirping and people eating and running around
playing.

The beach sounds like seagulls splashing and diving.
I hear people having fun.

The beach feels hot like summer and windy like a storm is
coming.

The wind blows my hair.

The beach feeling like sand on my feet or a sunburn on my
chest.

The beach makes me feel happy.

The beach tastes like salt in my mouth when I splash in the
water.

And sand gritty in my teeth.

The beach smells like low tide, seaweed, dead crabs and
fish.

The air can smell like sunscreen.



Photo by Kristina (Casanova) Law

The air smells fresh and
cool.

I see rocks, ocean
People climbing, playing
Frisbee with their dogs.

I see towels, sun hats,
umbrellas.

And boats, maybe a
shark or a whale.

The beach makes me feel calm.

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LathamCenters
Passage to a brighter future

Latham Centers, Inc. is internationally renowned for its expertise and success in working with individuals with PWS, a rare genetic disorder with no known cure. Latham Centers is accredited by the Council on Accreditation.

About the Author:

Patrice Carroll earned a Master of Social Work from Simmons College in Boston. She is the co-chair of the PWSA(USA) Professional Providers Board of Directors, as well as the United States delegate for IPWSO. Patrice is co-author of the *Living Healthy with Prader-Willi Syndrome* cookbook series. In addition to her experience with developing person-centered vocational programming for people with PWS, she shares her expertise at conferences and workshops locally, regionally, nationally, and internationally.



From the Author:

This publication is geared especially for the non-medical people working with children and adults diagnosed with Prader-Willi syndrome. Like myself, there are so many people in and out of your children's lives who do not have a medical degree but still need to have a deep understanding of the brain, the body, and how people with PWS can be successful despite the challenges that inevitably come with the syndrome. I hope that this booklet serves that purpose exactly.



This book is dedicated to the residents at Latham Centers. Through perseverance and determination, we witness you grow into lifelong learners and caring community members. Throughout the following pages you will see samples of their poetry, giving you insight into their complex and magnificent mindsets.

see me as me

by Tiffany

Look me in my eyes and tell me that “I am worth it”

look me in my eyes and tell me that
you understand

look me in my eyes and tell me
that I belong

look me in my eyes and tell
me that I can get through
this because we are all fighters
and we can get through any obstacles
that we may be faced with.

we are blessed to have loving and
supportive heroes by our side.

we will not give up

we will not

we will not

we will not give up

We will not fail

we will not

we will not because we are constant fighters
and will always be.



Chapter 1:

Understanding the PWS Mindset

Prader-Willi syndrome is a medical condition. Unwanted behaviors are a result of a dysfunction in the brain and not a choice to behave inappropriately. When the person with PWS is to the point where they are feeling out of control due to high levels of anxiety, it is not within their control to stop these behaviors. It is not a choice!

Manipulative behavior is common when the individual is feeling that they are not in control or are worried about the next step, the outcome, the way in which an activity will be managed, or what the expectations of them are.

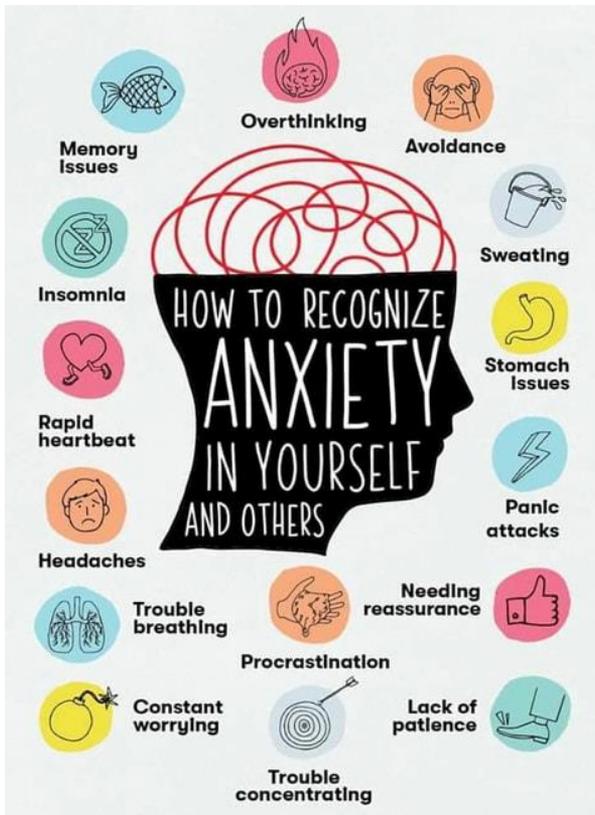
But remember that the list of what is good about the person with PWS is far longer than the list of challenges. Use these strengths in every interaction. Develop routines and programs based on strengths and work up to higher demands. Catch positive interactions in the moment and use praise as much as possible. The person with PWS wants to do the right thing and wants to be successful. Use praise, relationship-based activities, and as much as possible (and when it is a safe option), ignore the unwanted behaviors.

Manipulative behaviors are a direct result of anxiety. Low anxiety and trust in their caregivers is the key to a successful program. The following chapters outline strategies to help someone with PWS live his or her best life.

Remember that you're doing a great job, and that:

- anxiety is the overriding emotion

- the goal is to keep the anxiety level down
- someone with PWS and high anxiety thrives with a predictable schedule



<https://www.namikenosha.org/anxiety-disorder.html>

Anxiety: The things that work

- Have a plan — a successful plan is detailed and lists steps and expectations clearly.
- Have an out if anxiety is too high. Unless the activity is health related, it is likely okay to cancel or

postpone. Keeping anxiety down is your goal.
Good things happen when anxiety is low!

- If the individual embellishes the truth as a result of anxiety, it is likely a result of feeling out of control. The more control, choices and options that can be made available, the less likely this is to happen.
- If skin picking occurs as a result of anxiety, remember that this is not a choice, it is a compulsion resulting from a response to stress likely to release endorphins. In that moment of anxiety, it is not as simple as asking them to make a better choice; this is out of their control in that moment. This is also true for ritualistic behaviors. Rather than focus on the behavior, instead provide the individual with a coping tool in order to distract and redirect; i.e. anything that keeps someone's hands busy, such as a stress ball.
- It is common to see mood fluctuations in a response to the changing environment. People with PWS tend to overreact to environmental changes and we, as caregivers, should anticipate that and

communicate that we are aware of the increase in anxiety and offer support.

- Reading can serve as a great coping skill for people feeling anxiety.

Pictured: Latham students read a book donated by a local author.



Executive Functioning Disorder

Generally, individuals with PWS live with an Executive Functioning Disorder (EFD) which consistently challenges them. Often our brains compartmentalize what we need to do into steps...whether we're planning to take a shower or planning a wedding. With EFD, individuals have difficulty starting a task, and even more difficulty finishing a task.

Oftentimes, someone with PWS avoids the overwhelming challenges of EFD by shutting down, attempting to manipulate, exhibiting aggressive behaviors, or skin picking.

Processing Speed

Often, if you give someone with EFD multi-step directions, only the very last step will be heard. At times when the individual is calm and focused, multi-step functions are appropriate. When anxiety is high, even a routine task is difficult. You may be frustrated that a person who can complete a task with no assistance one day is suddenly acting as though they don't know how to do the assigned task. This is not non-compliance or attention-seeking — anxiety disrupts their ability to complete tasks, communicate effectively, follow rules, and focus. Therefore, we need to give one step directions unless they show they're able to do more. They'll show they can handle more by finishing the one-step direction and then asking, what's next? That's the cue that they are processing more efficiently.

To expect individuals with EFD to “go with the flow” and to be “flexible” are not options. This is not something that can be learned! Do not expect them to be flexible. It is not

fair to them and will only lead to frustration. Start and end every interaction with a positive comment. When struggling with concrete tasks and with “going with the flow,” one of our students at Latham Centers will often refer to her ‘flexible brain,’ and will say, “Patrice, I need to use my flexible brain today.” You may try using this verbiage when working with the person in your life with PWS.

Individuals also have a very difficult time judging what an appropriate response should be. Their reaction may not meet the situation at all. Individuals with PWS are often perceived as overly dramatic, non-compliant, and lazy.

This is not true! Individuals with PWS have sometimes been characterized as egocentric. On the contrary, most often, they are not being selfish or rude. If someone is being tended to before them, in their mind, this is not fair. What you can say is that you understand how they are feeling but regardless of what they say or do, you will be addressing the other person first. You can say that you know they’re upset and that as soon as possible, you will work with them.

Tools are available to help in this conversation. A scale of 0-5 can be utilized: a lost crayon would be a 0 while a serious emergency would be a 5. There will be a vast difference in their response to being asked to wait or being told that something is not possible etc. based on their level of anxiety in that moment. Please see chart on page 7.

If possible, we suggest completing non-preferred activities before preferred, and keeping expectations high but not to the point that someone can’t achieve.

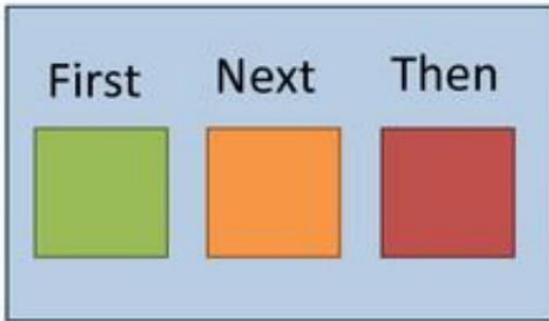
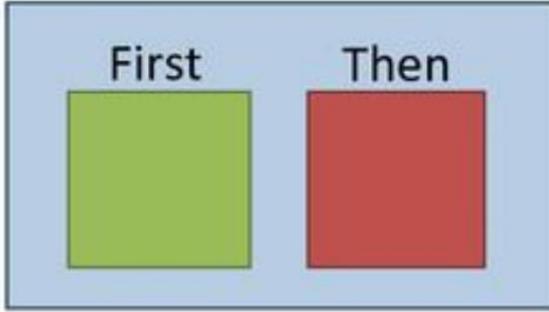
What works

1. Sticker Charts: (unique to the individual)
2. “How Big is My Problem?” Chart (page 7)
3. “First, Next, Then” Chart (below)

How Big is My Problem?

5	Emergency You definitely need help from a grownup (fire, someone is hurt and needs to go to the hospital, a car accident, danger).	
4	Gigantic problem You can change with a lot of help (getting lost, hitting, kicking, or punching a friend, throwing or breaking things, bullying).	
3	Big problem You can change with some help (someone is mean to you or takes something that is yours, a minor accident, needing help calming down).	
2	Medium problem You can change with a little help (feeling sick, tired, or hungry, someone bothering you, being afraid, needing help).	
1	Little problem You can change with a little reminder (not being line leader, not winning a game, not taking turns, making a mess).	
0	Glitch You can fix yourself (changing clothes, cleaning up toys, forgetting favorite toy or blankie).	

<https://sunshine-parenting.com/how-big-is-my-problem/>



<https://www.pinterest.com.mx/pin/81768549465087389/>

Sensory Processing Disorder / Challenges Common for Someone with PWS

Proprioception – Due to low muscle tone, an individual with PWS and Sensory Processing Disorder (SPD) may not know how their body works in space and relation to the entities around him or her. They may appear clumsy and often will walk heavily. Someone with SPD may need more energy to get things done.

Vestibular – PWS infants are not able to move their heads back and forth due to low muscle tone, which is a prerequisite for balance. Thus, the vestibular sense never develops. People may think of kids with PWS as lazy; most often, it is because someone with an underdeveloped vestibular sense feels like they're going to tip over or fall down. However, it can develop later in life! The more vestibular exercises someone with PWS does, the more confident he or she is in movement, resulting in lessened anxiety. Jump rope, swimming, seesaw, swings, throwing a ball, walking through cones; anything that helps with balance is beneficial. The more balance exercises the person with PWS participates in, the more comfortable he or she will feel.

How sensory processing can become a coping tool: A Positive Environment

- Auditory
 - Positive: Soothing Music
 - Challenging: Noise Canceling Headphones
- Tactile
 - Positive: Smooth Textures
 - Challenging: Tags in Clothing
- Visual
 - Positive: Soothing Space/Mindfulness Room
 - Challenging: Overstimulation

My Head

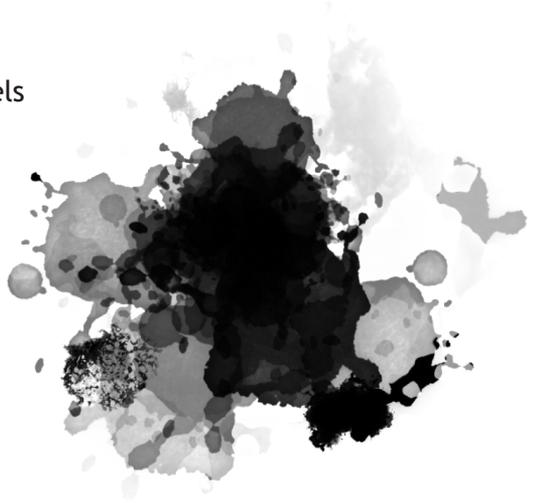
by Gabby

Sometimes my head feels
like it's going in
different
directions.

It's not clear and
things aren't split
into sections.

Like a boiling pot of
water, until it boils
over.

Sometimes I almost can't even see myself...like a
kid looking for something on the top shelf, just
out of reach



Chapter 2:

What Works

The person with PWS is unique. He or she has a different body, a unique way of thinking about things, and alternative modalities of communication. Following are several approaches that work.

Calm Voice

People with PWS will often match the mood that you are in. Remaining calm, focused and kind will help to model appropriate responses to stress, but it will also go a long way in defusing a situation if it has already escalated.



Listening to sounds in nature can be a great mindfulness practice, paralleling the concept of Calm Voice.

Validation

You may not agree with why the person is upset or having a negative response to a situation. It may not be something that would upset you and that's okay, you don't have to agree. But you do have to be empathetic and understanding that the situation is upsetting to them. Validate their feelings and understand that they would likely not choose to be this upset; it is out of their control. Be kind and listen.

Options

While individuals with PWS may struggle to make a choice between non-preferred tasks, it is an important skill. Give the person two concrete choices so that they have a voice in the decision-making process, and so that you can dictate the options. For example, "At this point we cannot go outside because it is raining. Would you prefer to color your favorite coloring book independently or play Legos with your brother?"



Face-Saving Way Out

Approach each situation with the understand that this behavior is not a choice. Allow the person to express themselves and agree that they will work on better responses to stress next time. This removes any feelings of humiliation, guilt, or shame which would lead to more unwanted behaviors.

Tools for the Next Time

Work on skill building daily when the person is at their baseline. Practice calming skills, using coping skills, deep breathing, and relaxation techniques before you need them. Practicing every day will make it easier to use these tools when the person needs to de-escalate.



Try to find the positive of everything. For example, even if the person didn't make the basket, praise their form.

Positivity

Emphasizing strengths and what is good and positive will

increase the person's self-esteem and improve their quality of life. Solely voicing deficiencies or pointing out what is wrong can have a profound, negative impact on a person's outlook on life. Being positive and optimistic will allow your loved one a chance to see the best in themselves which will allow for greater success and a better life overall.

Compassion

Face each day and each event with the knowledge that people with PWS have a much more difficult time getting through the day without experiencing high levels of anxiety. Be compassionate and empathetic, understanding that the person with PWS might be physically uncomfortable, mentally overwhelmed, and likely is not getting optimal quality of sleep, and yet they still face the day with ambition and excitement. Remember that if the person with PWS does have an incident, it was likely out of their control and not something that they would choose to do.

Avoid an Audience

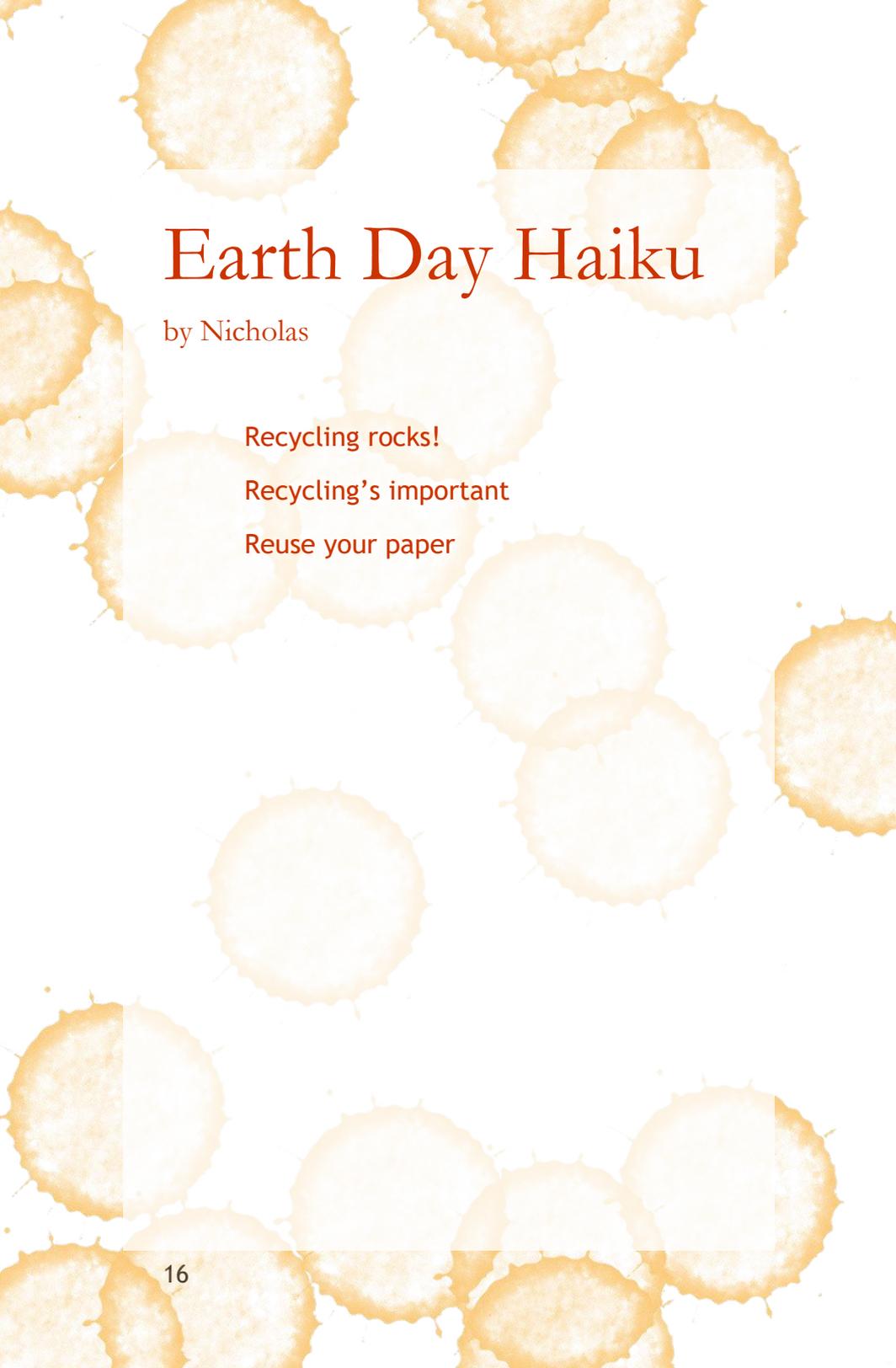
Give the person with PWS an opportunity to unwind in a comfortable place out of the public eye after an outburst. Allowing the person to move on and restart their day will be much easier to do if there is not an audience present. Embarrassment and fatigue often follow a behavioral outburst; it is best to allow them to rest and be alone (with supervision).

Non-Threats

Threats of losing something (a favorite item, a scheduled event etc.) during a behavioral event will only escalate the situation. Threats are not effective at best, and at worst will make the situation more volatile.

Commitments/Promises and Lack Thereof

Because a person with PWS is typically tied to a schedule, it is best not to promise something that you are not able to guarantee. Saying “maybe we can do this if you...” or “if you clean your room I will think about taking you to the zoo” are examples of poor communication and a set up for disappointment and failure. If you say maybe, it is often understood by the person with PWS as a hard yes and may lead to high anxiety and agitation. Promise only what you can guarantee. Keep things as black-and-white as possible and avoid the grey areas.



Earth Day Haiku

by Nicholas

Recycling rocks!

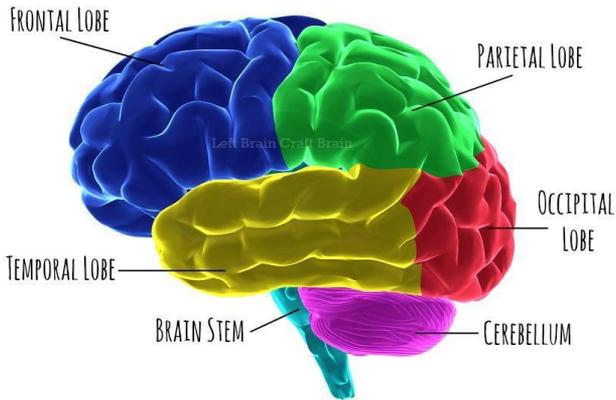
Recycling's important

Reuse your paper

Chapter 3:

Coping Skills

The importance of coping skills for someone with PWS



<https://tuxfordpsychology91.wordpress.com/3-the-brain-and-neuropsychology/>

A human brain is made up of many different parts, each of which takes on a different role. Brainfacts.org states,

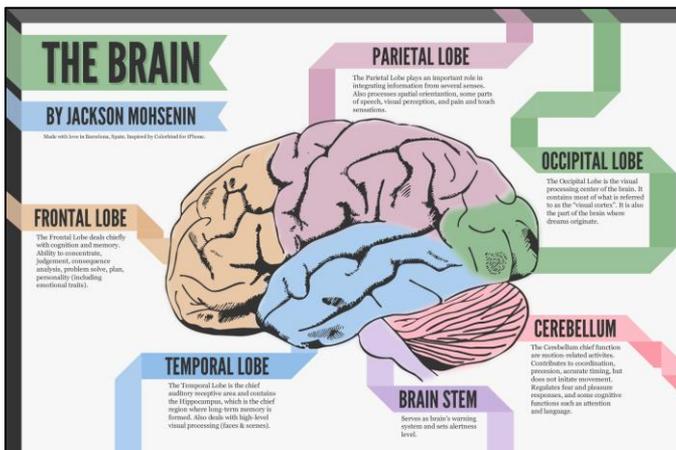
“No one brain region drives anxiety on its own. Instead, interactions among many brain areas are all important for how we experience anxiety. One potential explanation for how this works splits the brain into two parts: a cognitive brain and an emotional brain.

The frontal lobe, where all of our sensations and thoughts come together as one unified experience, is the cognitive brain. The amygdala, located deep inside the brain, is part of the emotional brain. According to this theory, we only feel anxiety when signals from the emotional brain

overpower the cognitive brain, and into our consciousness. If you can rationalize that, for example, snakes are rare in the woods you're hiking in (using the cognitive brain), then cognitive brain network overtakes and tames the emotional fear network.” (<https://www.brainfacts.org/diseases-and-disorders/mental-health/2018/what-part-of-the-brain-deals-with-anxiety-what-can-brains-affected-by-anxiety-tell-us-062918>)

Coping skills help steady nerves and override the emotional part of the brain by triggering other areas. Coping skills help individuals through challenges like transitions, as well as general anxiety.

Every individual finds different things soothing. While some like the feeling of rocking, others prefer the weight of a weighted lap pad. While some like the sound of music, others prefer a silent space with no distractions. Below, we've identified different challenges, along with suggested coping tools.



<https://visual.ly/community/Infographics/health/look-brain>

Coping Tools for...

Anxiety

- Weighted lap pads (Please consider the weight of the person utilizing the lap pad, and refrain from using the lap pad on the chest)
- Pulling thread (Preferred items include Burlap and cloth. Also, it's a great use of a sock that lost its pair.)
- Untying knots
- Soothing music
- Drawing
- Reading
- Quiet time
- Fidgets
- Therapuddy
- Hugs
- Hand Squeezes
- Mindfulness Breathing
- Time with pets



Coping Tools for... (cont'd)

Upcoming change and transitions

- Social stories: create a social story with someone which outlines the upcoming transition. The story may include the feelings the person may have, the things that may occur, appropriate reactions, and supports.
- Sensory stimuli
 - Auditory: soothing music
 - Tactile: smooth textures, brushing
 - Visual: soothing space, mindfulness room, small lights, projector lamps

Starting the day off right

- Schedule and Routine:
 - Create a morning routine that is consistent. Help the individual with necessary tasks and give them some time of independence if appropriate. By starting the day off right you've created a positive mindset for the next activity. A sample routine is below.
 - Creating an afternoon/evening routine will encourage appropriate bedtimes and regular transitions, as well as set you up for greater success the next morning.

My Morning Time Routine:
Time to get ready for school!



If the sun is up it's time to get up!

I go into the bathroom and check my list!

It's time to:

Use the toilet	Wash my face
Wash my hands	Put on my school clothes



Am I ready for school? Let's check my list!

Pack my backpack	Put on my coat
Put on my shoes	Tie my shoes
Smile!	



Now it's time to wait for my transportation!



Waiting can be hard sometimes but I'm getting better at it. I need to stay ready by the door so I can go outside when the van comes.

Here are some things that I can do while I wait:

Look out the window	Sing songs from the Lion King as loud as I want!
Use a coloring book	Draw pictures of Sonic

When the van comes mom and I will walk outside and I will start another great day at school.



Returning to baseline after an incident

- **Time and Conversation:** after an incident, you may see a few different reactions. Some individuals are emotional, others become quiet, many act as if nothing just happened. Rather than discuss the antecedent directly after the incident, most often, the best thing to do is give it time. Later you can

discuss how the person is feeling about the earlier incident, once time has passed, feelings have settled, and anxiety has been reduced.





Blue

by Annabell

The sky can be so blue, like us.

And sometimes sadness all above.

I wish everyone could spread their wings and fly
out beyond the dark night sky.

And with every flap of our wings, we push the air
beneath us, like a gasp of air that we needed.

We can all be guided by moonlight as we fly.

Chapter 4

Understanding PWS Behaviors

Planned ignoring is an effective skill to use when working with someone who acts inappropriately to gain attention. Before utilizing this tool, be certain that the behavior will not cause harm to the person or persons around them. Typically we see a person seeking attention through unwanted behavior because it has been beneficial and rewarding for them in the past. They act in an inappropriate way, receive attention immediately, understanding that this behavior gets them what they want in real time.

We suggest changing your response in order to change the unwanted behavior, i.e. ignore the situation.

Soon the person will see that the undesirable behavior does not get them the reward that it has in the past. If you are not yet comfortable with trying this on larger behavioral issues, then start small; practice with low level behaviors that do not directly interfere with programming. The bottom line is that we want to encourage positive or wanted behaviors and discourage negative or unwanted behaviors. The most effective way to do this is by giving attention to what you want to see, not what you don't want to see.

Here's how:

- Ignore any unwanted behavior unless the person or others are at risk of imminent harm.

- Praise and give attention any time the behavior is not happening, especially if it is at a time when you would typically see this behavior occur.
- Look for any way to praise in the moment, even when the behavior is happening. For instance, if someone is screaming or banging but is sitting down, tell them you are really proud of them for sitting, tell them you are happy to see that they wore a warm sweater on a cold day, notice and praise if their hair is combed or teeth are brushed, then immediately walk away and give zero attention to the outburst. Literally find anything you can to praise them for but ignore the unwanted behavior.
- When the unwanted behavior stops, do not recognize the behavior at all; do not say you are glad they stopped screaming, give no attention to what they just did. Move on with praise and recognition for other behaviors that are wanted or desirable.



Conclusion and Games



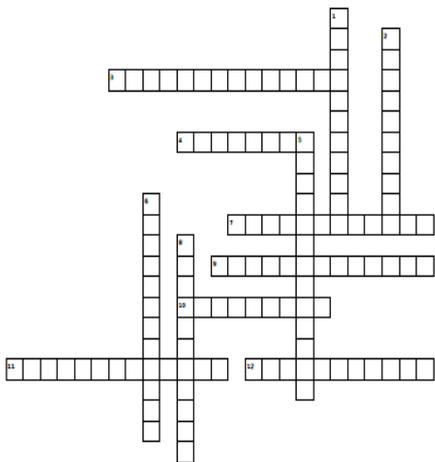
Our loved ones with PWS are complicated and amazing people. These complications lead to various scenarios, many of which can make the caregiver, or the person with PWS, feel doubtful or frustrated. We hope that you feel more equipped to handle difficult situations based on many of the topics reviewed. Ultimately, the list of what is good about someone with PWS is much longer than that which is challenging. We hope that from this you take with you a lesson of hope.

PWS word search

AHYKPWLMAOEHBUJIHXZO
LYJXUDUONPZJYLDLYZEU
MPITUITARYGLANDSPBJD
UOIHLDJWGSFZDWEOLQZ
STTZBBIVJSXXAHENTGEC
COFKKDCMYDYPPRSOSHSNH
LNWAHZPMHNVOUTLOASDR
EIQTESTOSTERONERLLOO
TARSDCLUESCESOHYAECM
OGCOMPULSIONSSSTPMERO
NEERZSHUTDOWNSVRUPIS
ENPXMHQYARDOAMNOSANO
XEGOFZKOTIVEQLPCAPEM
STBCOPINGSKILLSELNYE
AIRGXDTIAXHUCEJSBECK
TCYMVCYQDEBVYETSBAZY
IXBEAVLVAOFEVGNILUNV
ELETHARGYOOAVRTNOTMV
TQIFLKULMLJCCA ZGNZS
YVGUXCOSZULVQOGCVAYS

sensory processing	pituitary gland	coping skills	hypothalamus
compulsions	muscle tone	testosterone	sleep apnea
shutdowns	endocrine	lethargy	deletion
chromosome	hypotonia	genetic	satiety

PWS Crossword Puzzle



Down:

1. relentless hunger
2. process that converts what you eat into energy
5. hormone that stimulates growth
6. the only known treatment for hyperphagia
8. a drive to repeat actions despite the consequence

Across:

3. lack of deep sleep causes this
4. uncommon in PWS and can signal severe abdominal distress
7. part of the brain that regulates the metabolic process including hunger/satiety
9. a decrease in this makes diagnosing injuries and illness difficult
10. works with hypothalamus to control endocrine system
11. weak stomach muscles can cause this slow emptying of the stomach
12. a common habit that can lead to frequent infections and scarring

Connect with Latham Centers!

Weekly tips for the PWS community are posted on Latham Centers' blog. Written by Patrice Carroll, Latham's Director of PWS Services, the Tip of the Week is posted at lathamcenters.org/blog/category/tip-of-the-week/

Please visit us at LathamCenters.org for information about our ***LivingHealthy with PWS*** cookbook and email us at PWScookbook@lathamcenters.org with any questions or ideas.

Stay up to date on all things “PWS” in our Newsletter! Latham Centers publishes a quarterly LivingHealthy with PWS Newsletter. Features include seasonal weather and holiday preparation, highlights from our Children's and Adult Services Programs, ways to get involved in the PWS community, and helpful tips for parents, guardians, and caregivers. To be added to our newsletter distribution list, email PWSnewsletter@lathamcenters.org.

Visit us if you choose a Cape Cod vacation! Latham Centers' Admissions Team invites you to schedule a campus tour and learn more about our services and our outreach. Cape Cod is a wonderful place to visit any time of the year! Latham Centers also offers Virtual Tours. We welcome your inquiries at admissions@lathamcenters.org.



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