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Behavioral Challenges in Older Children and Adults

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Learning Objectives



- To describe the developmental onset and characteristics of the most common challenging behaviors in children (and adults) with PWS
- To learn strategies for prevention and management

There is a YouTube presentation on Developmental Tasks of the Person with PWS from infancy through adulthood that has skill sets for parents at each stage.

| Child | Family | Community |
|--|---|--|
| Interest in food; +/- weight gain; what is “ <i>my food, your food</i> ” | FOOD SECURITY Implement diet with calorie count & portion control | Teach school & other carers about PWS, diet & FOOD SECURITY |
| Reward, expectations & disappointment The TANTRUM | Create daily schedule; Set rules, limits and contingencies TRAIN | Identify & teach your “team” Avoid an audience! |

The PWS Story

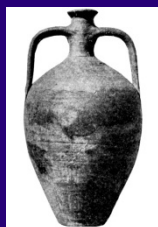
The PWS behavioral phenotype:

- Hypotonia & Failure to thrive
- Hyperphagia & Satiety deficit
- Impulse control problems
- Sensory processing & integration deficit -> Sensory hunger
- Excessive & repetitive behaviors
- Cognitive rigidity
- Stress sensitivity



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Clay Pots Research
Marjorie Royle, PhD



A Preliminary Description of PWS Behaviors Across the Lifespan: Stability and Change

PWSA-USA National Meeting: Scientific Day
Milwaukee, Wisconsin
July 2, 2008

What did we learn?



- Food *interest* increases around age 2-3 years, around the same time as the first tantrum occurs.
 - This may reflect maturation of the reward centers in the brain.
- Repetitive asking about events emerges as soon as kids can talk (3-4 years) and is actually more intense than talking or arguing about food.
- Temper tantrums and problems with transitions increased steadily, peaking around 8-10 years, and remained at high rates even in adulthood.
- Children do not outgrow their behavioral challenges, although older individuals display a trend toward fewer food related behaviors.

Challenging behaviors:

- Food related behaviors
- Temper tantrums
- Perseverative questioning
- Problems with transitions

Managing food-related behaviors

- Teach “my food, your food”
 - Don’t allow your child to eat off other’s plates.
- Avoid “just this once” - your child will never forget!
- Supervision is required in all food situations.

FOOD SECURITY



No doubt

No chance

No Disappointment

FOOD SECURITY

I know



I accept

I am content

FOOD SECURITY

- Implement FOOD SECURITY
 - My child knows what they will eat, how much they will eat, when they will eat it, and when they won't.
- Food security manages both food and behavior.
- Without FOOD SECURITY, you are constantly battling with your child's expectations, which inevitably lead to their disappointment.

When the child is not constantly thinking about food, they can use their mind for other things!

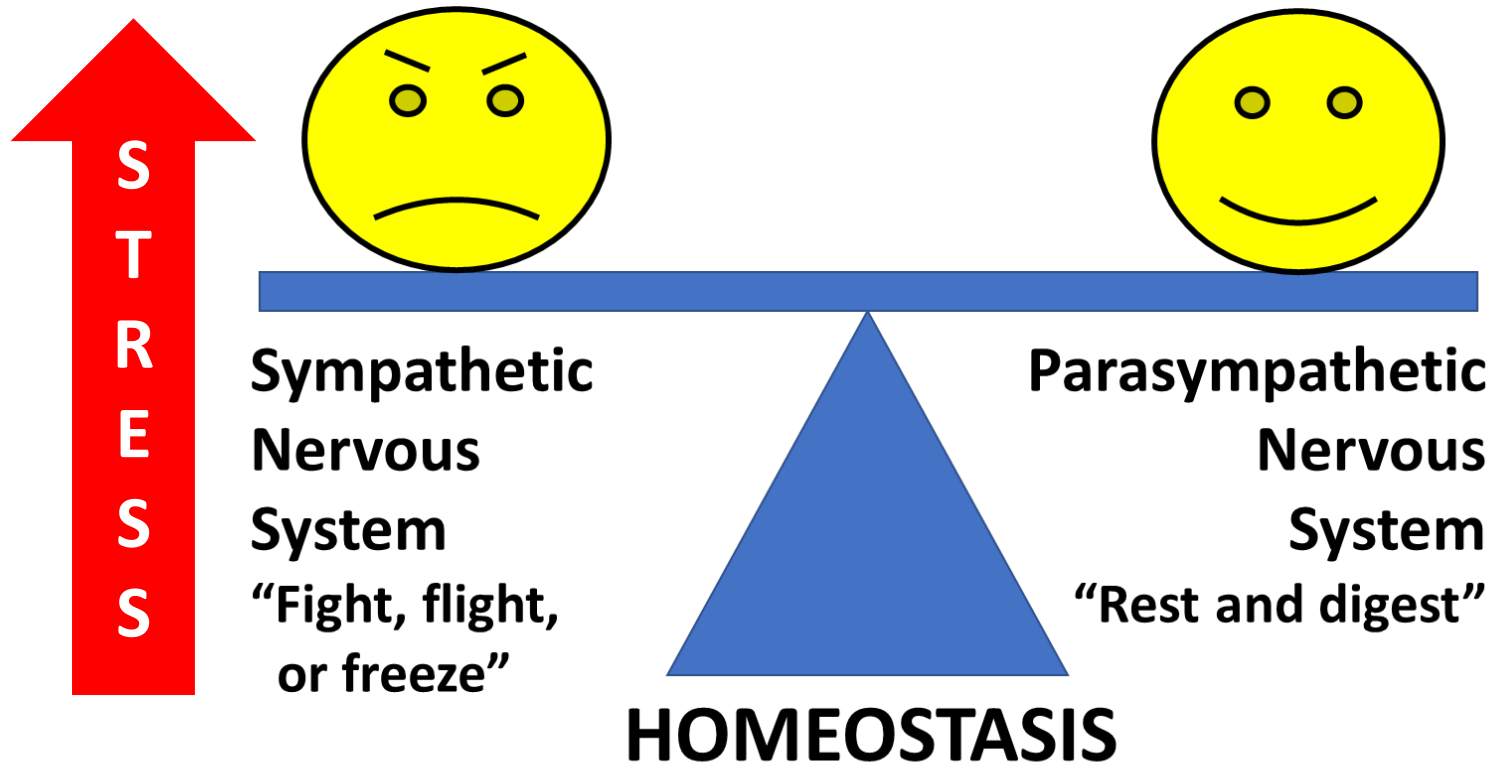
The TANTRUM



- It is a behavior that occurs when the child expects that something will happen and it does not.
- It occurs universally in children with PWS, similar to typical children, but more intense and lasts a lifetime.
- Each child's tantrum profile is unique.
- It is stress related.
- It is physiologically based and related to an imbalance in the nervous system of individuals with PWS.

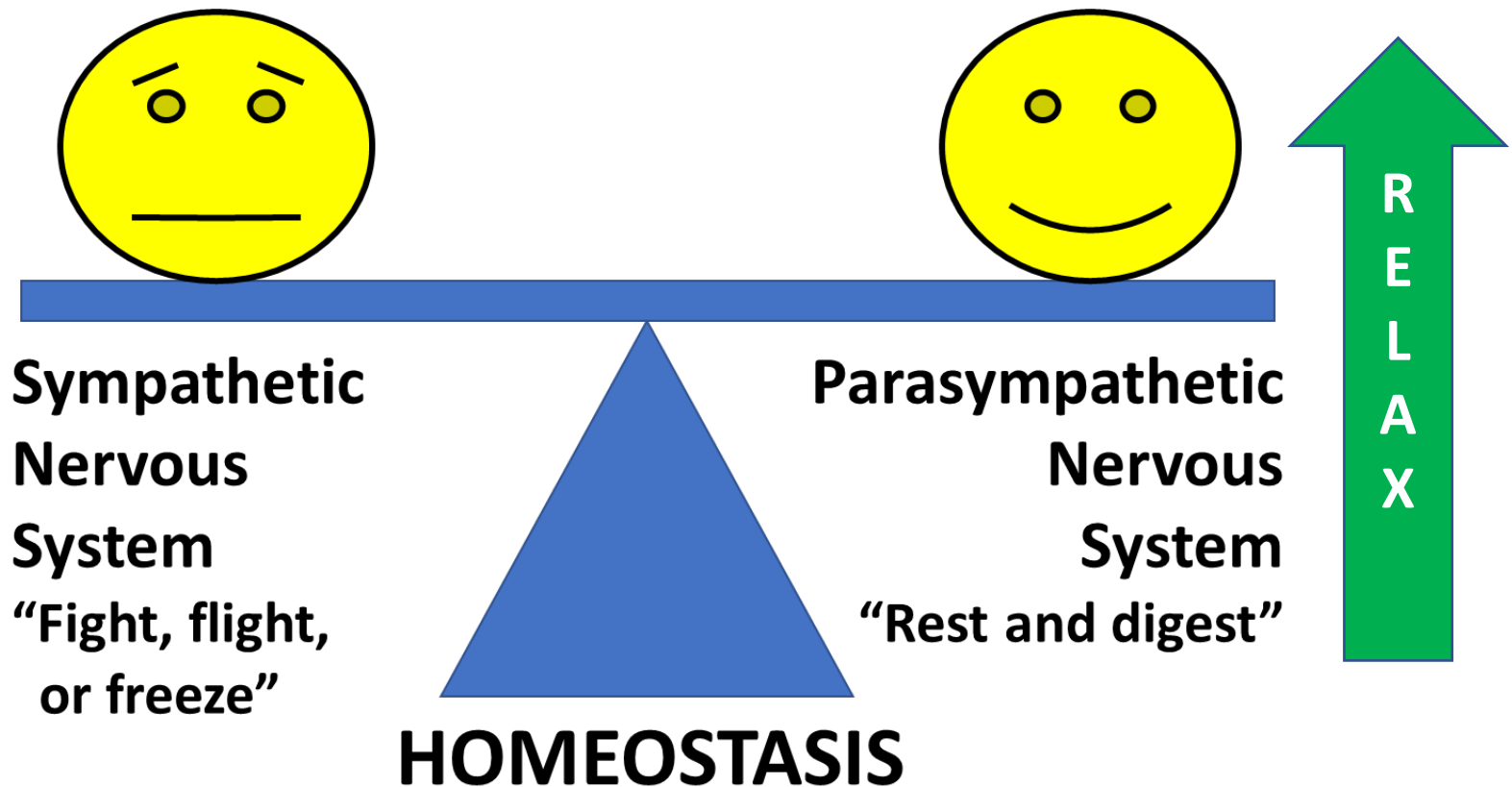
MAINTAINING BALANCE IN THE ANS

Activation of SNS with stress:

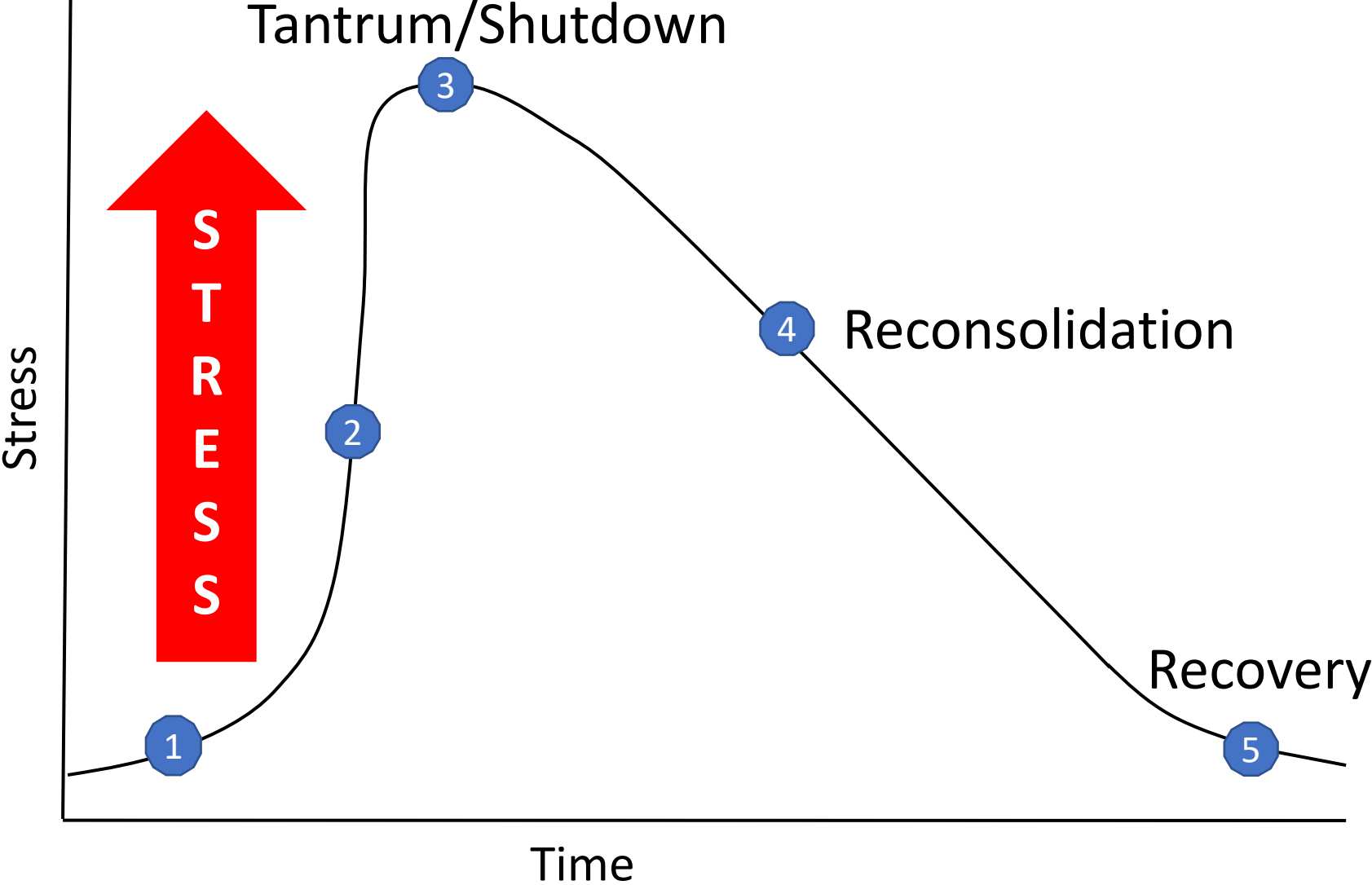


MAINTAINING BALANCE IN THE ANS

Achieving contentment through activating the PNS:



Anatomy of a Tantrum



Achieving contentment



- Knowing what will happen next
- Maintaining a routine
- Doing preferred activities
- Doing repetitive activities
- Exercise/stretch/breathe
- Sensory stimulation (chewing, hugs, message, etc.)
- Unconditional social support (love!)
- Autonomy (sense of mastery and control)

The TRAIN



T – Tool for

R – Reducing

A – Anxiety

I – Insecurity

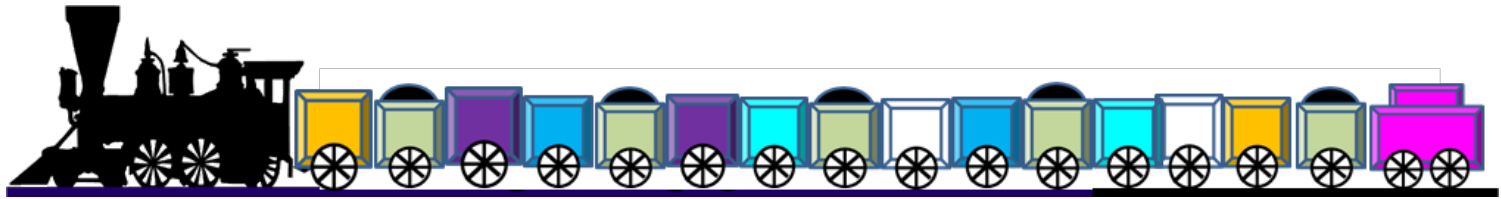
N – Noncompliance

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The TRAIN

- Linear schedule that orders daily activities by alternating non-preferred then preferred, to maintain flow across the day.
- Goal directed behavior increases mastery and self esteem.
- Routine fosters independence and autonomy.
- Knowing what to expect across the day reduces stress and anxiety.

The TRAIN



-  Meals and snacks
-  Hygiene and grooming
-  School/work
-  Exercise/sensory activity
-  Chores
-  Leisure
-  Sleep

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EVERYTHING SECURITY

I know



I accept

I am content

Repetitive questioning



- For your child...
 - They are uncertain and anxious.
 - They want to clarify expectations.
 - They want to talk to you.
 - It is hard for them to stop talking, listen and process your answer.
 - They have a need to know...
 - Who, what, when, where, how
 - They think everything is related to them!
- For you...

It is slow torture!

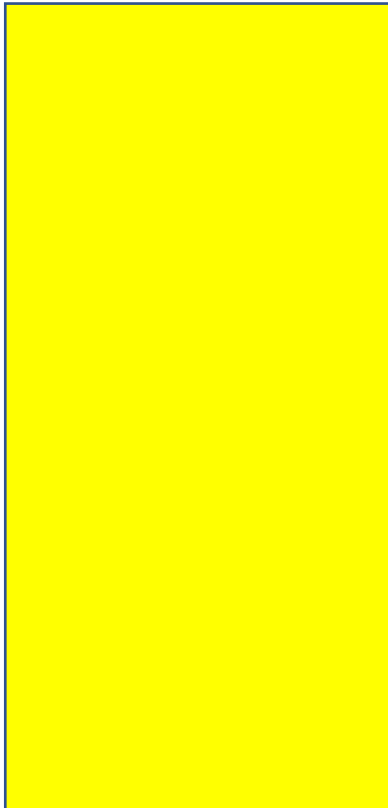
Managing repetitive questions

- If your child is questioning about activities, check the TRAIN schedule with them.
- Teach the child about the “Three times rule”
 - 1) Repeat the child’s question.
 - 2) Answer the question.
 - 3) Ask the child to repeat the answer, and when they can do this, let them know that you won’t answer the question again.
- Redirect the child’s questioning to a preferred topic, and model conversational skills

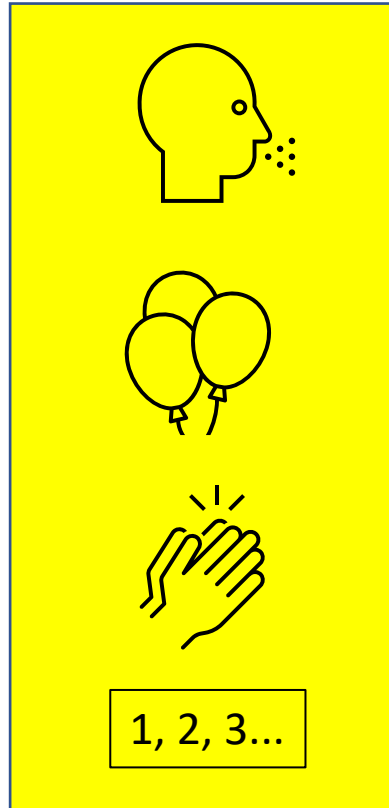
Managing changes/transitions

- Because you are the engineer of your child's TRAIN, you will know if something different is about to occur, and you can prepare your child for the change.
 - Announce the change.
 - Reassure your child that their food will occur in the order of the day: "First we fix the flat, then we go home, and then you will have your lunch."
 - Use a "flexibility card"

FLEXIBILITY CARD



Front



Back options



Managing transitions



- Your child has difficulty switching tasks.
- Your child has a poor sense of time passing.
- You can verbally cue your child about the need for task change and provide an additional verbal warning.
- Your child may benefit from a visual display of time passing by using a “time timer”.



Time Timer

An iceberg floating in the ocean. The tip of the iceberg is above the water line, and the much larger, submerged part is below. The sky is blue with light clouds, and the water is a deep blue. The iceberg is white and blue, with some snow on top.

FOOD

The Rest of PWS

Summary



- Challenging behaviors appear as the brain develops and the child learns
- A high degree of structure, consistency and predictability in the home decreases challenging behaviors and parental stress
- Proactive measures of FOOD SECURITY and the TRAIN provide the infrastructure to manage many challenging behaviors.

Thank you!

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Skin picking (occurs commonly, but not universally):

- As a habit behavior with opportunistic typography:
 - fingers, cuticles
 - arms, legs, face and scalp
 - nose, nasal septum
 - peeling skin from the soles of the feet
 - pulling out teeth, toenails
 - trichotillomania (hair pulling)

Skin picking (occurs commonly, but not universally):

- As an intense, severe, reactive behavior in the presence of ongoing stress:
 - gouging, self mutilation
 - rectal picking
 - vaginal picking

Interventions for Picking Behavior

- Prevention (lotions, sensory diet)
- Distraction, DRO
- Low attention, reinforce “healing”
- Non-contingent social stimulation
- Non-contingent sensory stimulation
- Extinction (barrier methods)
- Contingent behavior management
- Medications

Sensory Stimulation: Sensory “Diet”

Proprioceptive/kinesthetic:

- Sedentary physical activity
 - Chewing gum
 - Water play
 - Popping bubble pack
 - Squeeze balls
 - Skeins of yarn
 - Brushing
- Vibration
- Deep pressure; massage; weighted vest; weighted blanket; therapy balls
- Light massage