



Rectal Picking

Rectal picking is a manifestation of PWS stress sensitivity. This algorithm may help you to get to the bottom of it.

SUMMARY

Step I Identify your child's stressors

See boxes on *Timing*, *What is a Stressor*, *What's New?*, *HIGH/LOW Expressed Emotion* and *FOOD SECURITY™*.

Step II Decrease any stressor that can be changed

This may call for some real creativity. Avoidance, substitution, modification in the schedule, counseling for family members or or new child care or school personnel are occasionally needed.

Step III Increase your child's stress tolerance by increasing sensory input through stimulation

Your child's rectal picking is a form of self-stimulation for his/her sensory hunger which is part of PWS. In addition to reducing his stress in Step II above, you can help him by providing a more appropriate sensory experience than his rectal picking or other self injury. (See box on reverse side.)

TIMING

1. When did your child start picking or when did it get worse?

This question often leads to clues. The duration of the picking behavior may be a year or more but it's worth looking back to see what changed. What was new at the time the behavior began or what increased in frequency/intensity.

2. When does your child pick?

If the stressor is not daily, the timing of increases in your child's picking behavior may be a clue. Keeping notes on the behavior and attempts at the behavior may reveal that picking is diminished on weekends or during school breaks, etc. Is it related to **constipation**?

What is a stressor?

- Stressors may be tension, worries, anxieties, dreads.
- Stressors can also be something positive. Excitement and anticipation can also cause stress and stress symptoms: vacations, parties, competitions etc.
- Stressors can be sensory, such as loud noises, crowds or unpredictable situations.

High Expressed Emotion

(See Handout The HyperReactive Child at www.pittsburghpartnership.com)

- Stress sensitivity to vocal tone (not necessarily loud), usually angry, annoyed, scolding, peeved, even emphatic tones, have a profound impact on stress sensitive persons.
- Scour your child's life for exposure to vocal tone that may be stressful. Does your child complain about "yelling" at home. He means tone, not volume.
- Ask him/her about anyone with a "mean voice" at school. New persons in their life; even an otherwise very good teacher or aide who occasionally scolds may not be right for your child unless he/she can change the style.
- New discord in the family can cause stress, even if the child is not being addressed directly by the angry voices. Problems in the marriage or with a sibling, if they are resulting in high expressed emotion, can be contributing to the problem.

What's New?

- Look for any change in your child's life that precedes or correlates with the increased behavior.
- Examine each change from the perspective of the other boxes on this page: *FOOD SECURITY*, *LOW/HIGH Expressed Emotion*, and medication changes.
- New school/classroom
- New aide
- New teacher
- Changes of household members coming and going
- New medications
- New activity
- New behavior program

Medications

- In the “**what’s new?**” category, medication changes, new medications or increases in dose are easily overlooked since the change in medication may precede the change in behavior by weeks or months and the behavioral change can be gradual, further separating cause and effect.
- The primary culprits in rectal picking in our experience have been the SSRI category of drugs: Prozac (fluoxetine), Celexa (citalopram), Zoloft (sertraline), Lexapro (escitalopram) and other medications commonly given for depression, anxiety, or what is thought to be obsessive-compulsive disorder.
- Other medications that may agitate rather than calm include Abilify (aripiprazole) and the stimulant medications given for attention deficit disorder (dextroamphetamine and methylphenidate in various brands or formulations)
- A frequent misunderstanding is that the repetitive behaviors and preoccupations of PWS or the picking behavior itself are symptoms of OCD. This is not OCD and can get better **or worse** on drugs for OCD.

FOOD SECURITY™

NO DOUBT, NO HOPE, NO DISAPPOINTMENT

(Please see handouts on our website)

- Outside of Prader-Willi residential living or specialized hospitalization FOOD SECURITY™ is rarely perfect. However, when a child or adult is showing stress symptoms his plan for FOOD SECURITY™ must be carefully reviewed. Walk yourself mentally through your child’s week looking for possibilities and opportunities for **doubts** and **hopes** about food.
- Identify any time periods where FOOD SECURITY™ could be at all in doubt (in your child’s mind)
- Identify any areas of **false hope**. It could be unfamiliar persons or location where your child has received food in the past. When he is being exposed to a person or place that you believe may be associated with **false hope** remind him what the food plan is in positive terms e.g. “Mrs. Johnson knows your schedule and she will be preparing you a snack at the usual time “. Or: “We will stay at the mall for an hour and then we will go home for dinner.” Meaning: “We will not be eating anything at the mall.”

Step 3 Increasing Your Child’s Stress Tolerance.

Develop a Sensory Program

Rectal picking is a form of self management of the sensory hunger associated with PWS. A daily program of intense sensory stimulation of various kinds has greatly reduced skin and rectal picking in PWS. Sensory interventions include frequent, brief intervals of sensory stimulation built into your child’s day and can be included in his IEP.

Physical exercise/trampolines/swimming/weight lifting

Massage of scalp, feet, hands or neck and shoulders

Vibratory massage

Chewing gum 3 times per day; must return prior chewed gum to paper cup to earn next piece.

Oral sour sprays

Rocking chair or swings

Tug o’ War games

Mat exercises; being squashed under a beanbag chair.

Some Occupational therapists and Physical Therapists who work with Developmental Disabilities have a strong interest and expertise in sensory activities for children and adults with disabilities and can help you put together a program for your child.

Basic General Tips

- Sensory events can be brief, less than 10 minutes
- They should be frequent, three or more times per day
- They should be part of the schedule and noncontingent, meaning that they are not taken away for punishment or given as rewards for good behavior. In the case of disruptive behavior or a shutdown, the sensory schedule is merely postponed until the child is able to participate.

Understanding the Etiology of Picking Behavior in PWS:

