

Pittsburgh Partnership

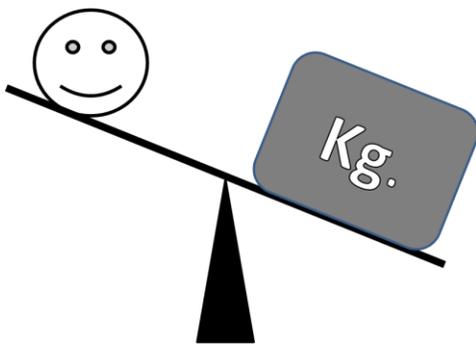
Specialists in Prader-Willi Syndrome

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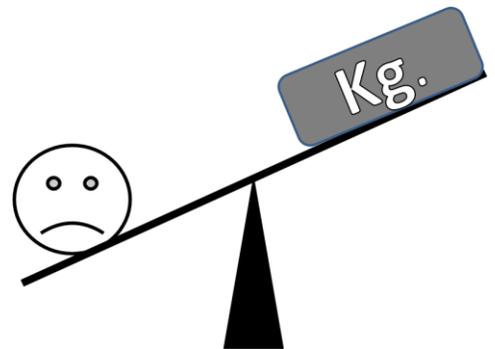
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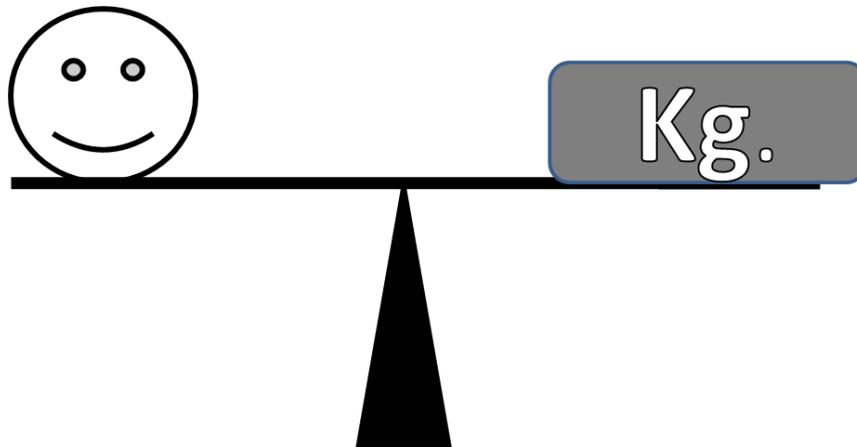
Prader-Willi Syndrome Food Security Basic Concepts



Families and professionals often mistakenly believe that the patient cannot be happy unless he has as much food as he demands. Because efforts to limit food, if attempted without establishing food security cause increased stress and behavior problems.



When *Food Security* is fully implemented, weight and behavior are both managed successfully and simultaneously.



Food Security

Remember: "Food is STRESS"

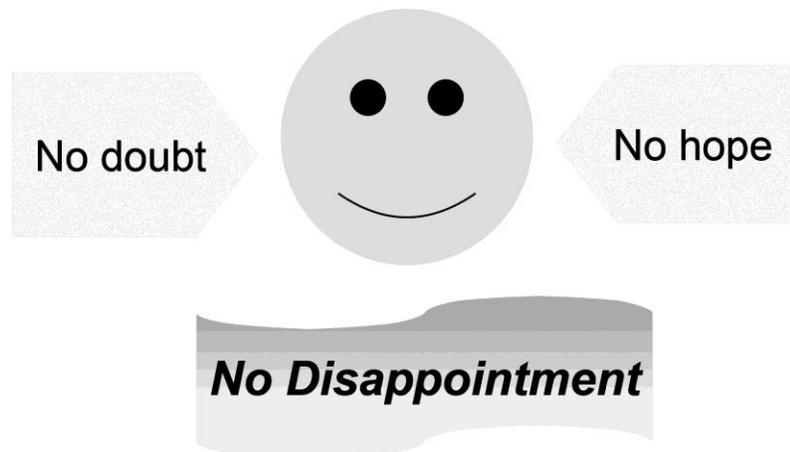
Food Security includes:

NO DOUBT

The person with PWS is able to relax and think less about food when he knows the plan for his food each day. This is achieved by a predictable routine for the day in which meals are scheduled reliably among his other activities. Focus on the *sequence* of events and not the *time* of each meal. Advanced planning assures the individual of what activities will precede the meal and which will follow. Advanced menu planning provides him with expectations which will be reliably fulfilled.

NO HOPE (NO CHANCE)

As children get older, opportunities for food acquisition increase and they require more measures to assure that they are not hopefully scouting for food all day. Chances to obtain food are stressful and therefore, as much as possible, should be eliminated. The measures taken will depend on the individual's history and capability of food acquisition



Successful Behavior Management of PWS means that uncertainty about food must be eliminated as much as possible. Advance planning of meals, a schedule of all the day's events with the place of meals clearly identified, reminders of these plans and a behavior program which requires completion of one task before the next activity (including meals) is begun, all contribute to successful behavior management.

FOOD SECURITY for PWS

Food insecurity contributes to over eating, poor nutrition and obesity. **FOOD SECURITY** is defined as *the ready availability of nutritionally adequate and safe foods with an assured ability to acquire acceptable foods in socially acceptable ways*. The principles of **FOOD SECURITY** are:

- **No doubt** when meals will occur and what foods will be served.
- **No hope** of getting anything different from what is planned.
- **No disappointment** related to false expectations.

Here are some ways to achieve FOOD SECURITY:

1) Secure food accessibility across *all* settings by:

- a) Controlled access to:
 - i) Refrigerator, freezer and pantry
 - ii) Vending machines
 - iii) Money

- b) Avoiding any spontaneity related to food
- c) No snacks on demand
- d) No food left out
- e) No “free” foods or beverages
- f) Absolute portion control
- g) Pre-packaged condiments

Have a Plan

A person who needs food security should never enter a “food situation” without knowing what the plan is for maintaining his or her dietary needs.

Some individuals need all of these measures; others only some.

2) Supervise food exposure:

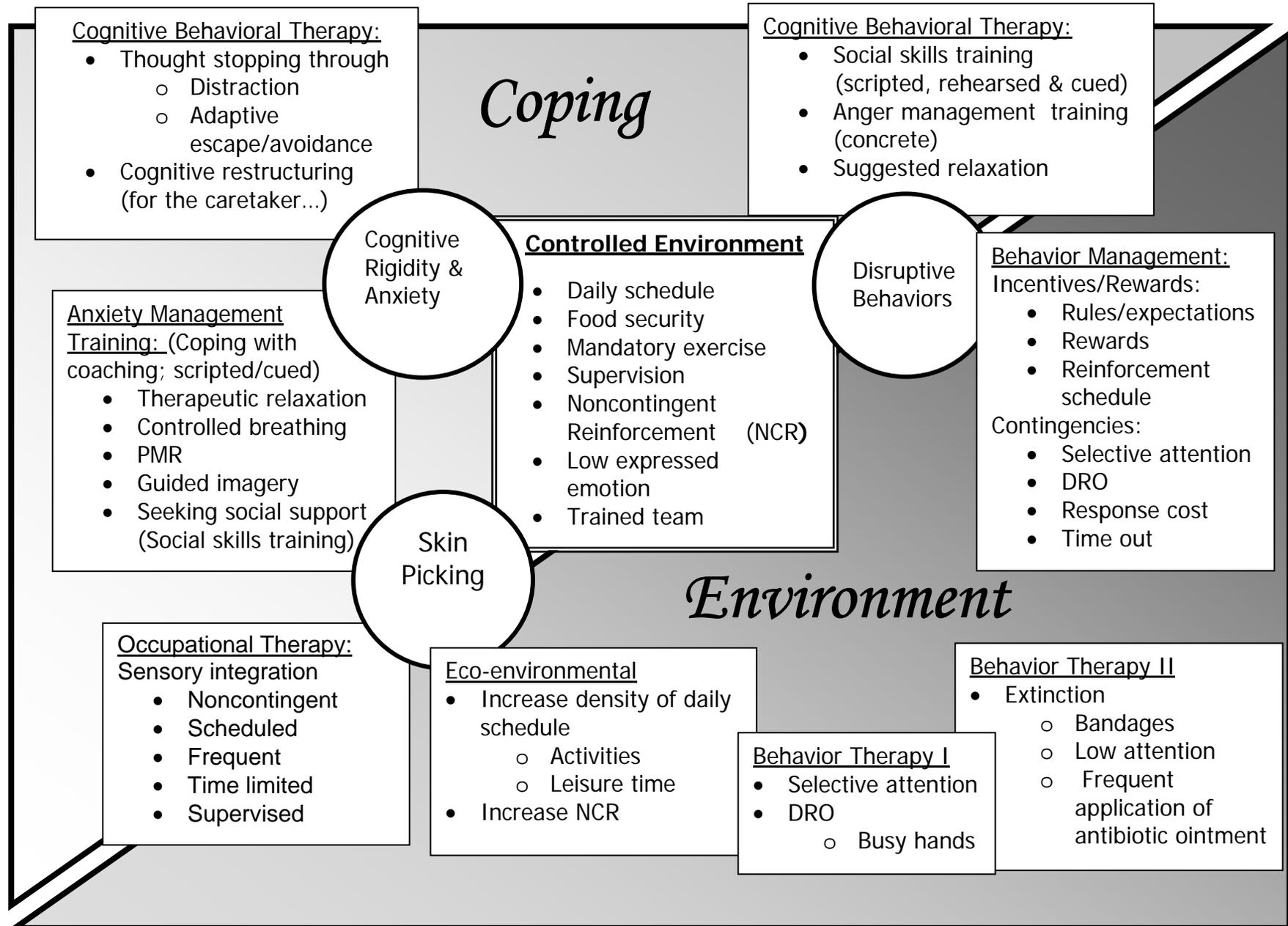
- a) At stores
- b) During food preparation and mealtime
- c) During special occasions (birthday parties, seasonal celebrations, etc.)
- d) When dining out in the community...
 - i) Access menus from restaurants in advance and decide what will be ordered.
 - ii) In general, buffets are understood to be “off limits?” Or, if unavoidable, it is understood that the plate will be prepared by someone else.

3) Post the schedule for mealtimes and snacks.

4) Post the schedule and the menus for meals and snacks.

5) If necessary, because of raised expectations or anxiety, avoid places and social situations associated with excess food

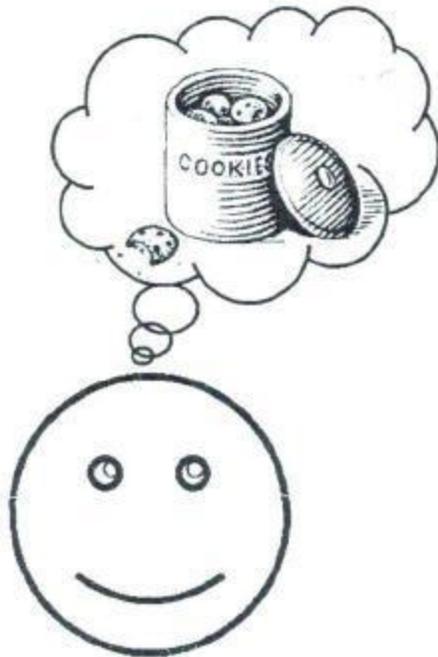
Psychological Treatment Toolkit for PWS



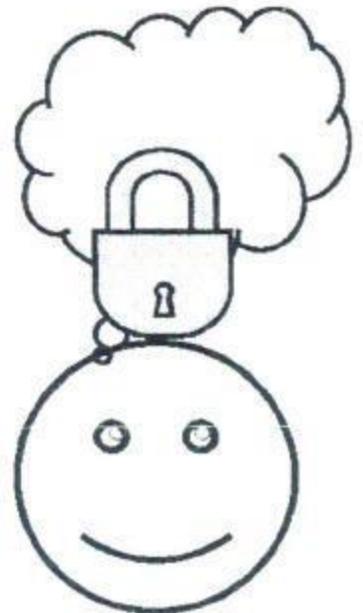
Food Security is a State of *Mind*

FOOD SECURITY is the essential ingredient for managing the food related behaviors associated with PWS. FOOD SECURITY has been defined as *the ready availability of nutritionally adequate and safe foods with an assured ability to acquire these foods in socially acceptable ways*. In PWS, FOOD SECURITY provides **no doubt** when meals will occur and what will be served; **no hope** of getting anything different from what has been planned, and **no disappointment** related to false expectations. FOOD SECURITY is achieved by securing food access across all environments, supervising food access across all environments, posting mealtimes and menus, and training all team members. When the individual with PWS is experiencing FOOD SECURITY, that is, **no doubt, no hope** and **no disappointment** related to food, a generalized behavioral improvement typically occurs. For this reason, FOOD SECURITY *is the mainstay of PWS management before considering the implementation of behavioral interventions and pharmacotherapy*.

From "Pittsburgh Partnership Psychiatrists' Primer for Prader-Willi Syndrome" by Janice Forster, MD and Linda Gourash, MD



**FOOD
SECURITY
MEANS
PUTTING A
LOCK on
the
THOUGHT**



FOOD SECURITY Checklist for the Family

NO DOUBT

- My child has a menu posted. He/she always knows what he/she is eating for the next meal.
- My child takes his/her lunch to school/work.
- My child is rarely disappointed about food./ he always gets exactly what he is expecting. 😊
- My child sometimes corrects others about his/her diet. 😊
- My child knows when he/she is going to get a treat well in advance. There are no surprises.
- My child never receives unplanned treats
- My child rarely asks about what he/she will be eating. He/she already knows. 😊
- My child knows when his/her meals are scheduled during the day. 😊
- I never threaten my child that a meal will be delayed or changed in any way.
- My child has scheduled zero calorie treats built into his /her daily schedule.
- My child knows that if his usual menu is disrupted for any reason he can always count on the same “alternate”.

NO HOPE

- My child does not have free access to calorie free foods or beverages other than water.
- During meal preparation another member of the family is assigned responsibility for watching my child with PWS.
- My child rarely argues/tantrums about food. 😊
- When we go to a buffet at a restaurant or party my child knows that I will be preparing his/her plate.
- My child has someone assigned to be with him/her during lunch at school/work.
- My child does not keep his/her own money.
- At this moment there is no unlocked food anywhere in my home.
- [As far as I know] My child has not successfully stolen extra food in the last 2 weeks. 😊
- We have a plan for every special occasion and my child knows what the plan will be well in advance.
- Even though my child knows and expects his/her diet, I know that he cannot be trusted to maintain it him/herself. 😊
- My child never prepares his/her own plate.
- When we “dine out” or “order out”, we get the menu in advance so that my child knows exactly what he/she may order.
- My relatives/neighbors never offer my child food. I have successfully explained to them why they must never do this. 😊

😊 = signs of success. If you have all of these signs of success your food security is complete!

FOOD SECURITY Checklist for the School/ Workplace

NO DOUBT

- This student/worker has a menu posted. He/she always knows what he/she is eating for the next meal.
- OR
- This student/worker brings his/her lunch to school/work.
- During any food preparation another member of the team is assigned responsibility for watching this student/worker with PWS.
- This student/worker is rarely disappointed about food; he/she always gets exactly what he/she is expecting. 😊
- This student/worker sometimes corrects others about his/her diet. 😊
- This student/worker knows when he/she is going to get a treat well in advance. There are no surprises.
- This student/worker knows that if his usual menu is disrupted for any reason he/she can always count on the same “alternate”.
- This student/worker rarely asks about what he/she will be eating. He/she already knows. 😊
- This student/worker knows his/her schedule every day.
- This student/worker knows when his/her meals are scheduled during the day.

NO HOPE

- This student/worker is never offered food that is not planned in advance and cleared with his/her family or residence.
- I never threaten this student/worker that a meal will be delayed or changed in any way.
- This student/worker has scheduled zero calorie treats built into his /her daily schedule.
- This student/worker has no access to calorie free foods or beverages other than water.
- This student/worker rarely argues about food. 😊
- This student/worker has someone assigned to be with him during lunch at school/work.
- This student/worker has no opportunity to get food during transitions or transportation. He/she is continuously supervised or the food is stored out of reach.
- At this moment there is no unlocked food anywhere in the areas where this student/ worker is permitted.
- This student/worker does not have access to money or to vending machines.
- We have a plan for every special occasion such as birthdays or holiday celebrations and this student/worker knows what the plan will be well in advance.
- Even though this student/worker knows and expects his diet, the entire team understands that he/she cannot be trusted to maintain it him/herself. 😊
- This student/worker has not successfully stolen extra food in the last 2 weeks. 😊
- The other students/workers never offer this student/worker food. Our team has successfully explained to them why they must never do this. 😊
- Our team never uses treats as unplanned rewards

😊 = signs of success. If you have all of these signs of success your food security is complete!