



## **Pittsburgh Partnership**

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### **Making Changes**

*The following remarks are for parents to use when trying to implement changes in their daily management of a child or adult with PWS. This handout could also be a useful guide for professionals working with a family and we urge families with older children who are especially resistant to change to work with a professional in behavior management even if a persons experienced with PWS is not available. Parents know and professionals need to understand that backtracking with PWS is especially difficult but they will accept new limitations and rules if they are presented with a clear plan with built in rewards and incentives. We have a separate handout on building **Behavior Plans**.*

**If your child is young, under the age of 10-13 years, consider a more robust plan than he/she appears to need at the moment. He/she will accept your plan more readily now than a *change* in program at a later date and greater date. As he gets older and more able to obtain food, you may have to put restrictions into place that he will resist.**

**There are many components to a successful program for behavior management and food security, the program itself need not be complex and the components can become second nature and routine. You can think of this in 3 stages:**

1. **Plan** your program privately as parents
  - a. Decide which features are essential and non-negotiable
  - b. Decide which aspects are modifiable according to your child's preferences.
  - c. Write it out and make visuals ((Charts, menus, schedules) that will be aids to explaining it to you child.
  - d. Decide whether to implement all at once or in stages
2. **Present** it to your adult/child with emphasis on his opportunities to make choices and on the rewards and short-term benefits available to him. Do not expect that *your* goals will motivate your child. E.g. You want to help you child be ready for school in the AM; you are going to use computer time as an incentive.

You do not say, "We have a plan to teach you to be ready for school on time."

Rather, you say, "We have a plan for you to earn more time on the computer!"

3. **Implement** the program using daily reinforcers and earned weekly recognition of successful adherence to the program. Visual reinforcers can be age-appropriate even for adults. For younger children, colorful charts and stickers are effective. They should be posted where the child can see them and commented on daily by both parents. For older persons, graphs and data charts are reinforcing. Your child may enjoy having his own web page and blog where he can post his progress with charts and photos. Family members should log into the web page regularly and comment verbally and online.

Components of your plan will likely include in some form:

- Schedule Plan
- Menu Plan
- Exercise Plan
- And if needed, Specific Behavior Plan (targeting problem behaviors)
- Charting and Rewarding Success Plan

## Schedule Plan

**The Schedule of Events/Activities** is not based on the hour as much as the sequence of events before and after meals. This sequence helps keep the child oriented and less anxious about meal events

- a. Activities including meals, rest and exercise

Use the sequence of events to help your child move through the day. Convert warnings and threats into encouragement: e.g.

Rather than:

“Hurry up, or we will be late.”

Or worse:

“If you don’t hurry, we will have to skip breakfast.” (Use at your own risk!)

Say:

“As soon as you are dressed, we will have breakfast.”

- b. System of incentives that are built into the day; the frequency needed will depend on frequency of dawdling, mental age of the child, etc. For guidance on choosing and using incentives, see our handout on **Behavior Plans**.

## Menu Plan

### Designing a program for FOOD SECURITY with or without needed weight loss

FOOD SECURITY refers to the psychological state of the person. Food security may be remembered using the mantra: **NO DOUBT NO HOPE (NO CHANCE), NO DISAPPOINTMENT**. We have identified these 3 types of events as triggering a large proportion of the behavioral problems in PWS.

**No doubt:** Persons with PWS become anxious about food. They do not handle uncertainty about food. If they know with certainty when and what they will be eating they are usually much less anxious and less perseverative about food.

**No Hope (No chance):** even the possibility or chance of obtaining extra food creates anxiety because it creates uncertainty or disappointments. Avoiding hopes of getting food takes even more advanced planning than eliminating doubts.

**No disappointment:** Unfulfilled expectations can trigger major behavioral events.

Meal Plan includes:

1. Where the meals fit into the schedule of events
2. Dietary content (see below)
3. Serving size, which is not specified in writing for the child but is written out for the servers and is learned by the child through experience. The child/adult usually **does not measure or serve self** since this skill does not translate into independent functioning and can cause stress and conflict.

**Snacks** are optional and based on your child’s expectations for his age. He does not need extra food more frequently than other persons his age. It is essential that snacks are scheduled and do not EVER occur spontaneously or sporadically. If the schedule is disrupted by emergency or unforeseen events, meals and snacks can be postponed or combined with a meal but never cancelled. Once your child understands this, his tolerance for schedule disruptions will improve.

Make your self a grid with key elements:

|           | Sunday                           | Monday | Tuesday | Wednesday | Thursday | Friday | Saturday |
|-----------|----------------------------------|--------|---------|-----------|----------|--------|----------|
| Breakfast | Cheese and egg                   |        |         |           |          |        |          |
| Lunch     | turkey slice and fruit           |        |         |           |          |        |          |
| Snack     | nuts                             |        |         |           |          |        |          |
| Dinner    | Chicken & fresh leafy vegetables |        |         |           |          |        |          |
| Snack     | yoghurt                          |        |         |           |          |        |          |

Changing the diet:

Suppose you decide that you wish to begin a gluten-free diet or some other change in your child’s menu. Depending on how rigid and aware the child is, this can be a challenge but here are some guidelines.

- Do not attempt to eliminate any food while it is still in the house. There may be other foods in your house that your child does not eat but once a child is used to eating a particular food, it will be much easier to change his expectations if the food is simply unavailable.
- Emphasize what the child will be eating. Try not to mention the food that has been removed from the plan.
- If the child asks for an item which you are removing from his diet, tell him what he is having instead and tell him that the food is not available. If he whines and tantrums you should sympathize with him. Do not make any promises about another day and if possible do not reveal that the food has been eliminated from his diet plan for good. Take it one day at a time.
- You may decide to show the changes on his written plan or not depending on what you have learned to expect from the child. The plan gives security but when you are making changes, the plan in writing will reveal that the food is not ever going to be available.
- The child will protest far less if he believes that his protests have **NO HOPE, NO CHANCE** of success. He will also accept changes if he has **NO DOUBTS** of what he will be receiving.

## Exercise Plan:

Exercise burns a few calories, but more importantly it supports muscle tissue and pulmonary function at all ages. It stimulates mitochondrial production, possibly an important component of the lethargy associated with PWS. It also provides a source of sensory stimulation to the brain and increased depth of inspiration that decreases stress. Exercise also affects how well the pancreas works in response to a carbohydrate load.

A short walk everyday is useful to maintain the expectation that exercise is a daily affair. You family and your child may take 1-2 days off per week without physical detriment, but too many days off make it more difficult to maintain the habit or expectation. It is best to plan the day off into the weekly schedule rather than creating the expectation that exercise can be skipped on short notice.

We have seen dramatic pulmonary benefits to exercise in persons who are overweight. Exercise is the **best** treatment for fluid retention (often noted as swelling of the legs) in overweight persons with PWS.

Alternate walking with other aerobic activities only if your child can bicycle, swim or use exercise equipment **EFFECTIVELY**. Splashing around in the pool does not count as exercise. Swimming laps does.

Body building/weight training research (in nonPWS) is quite advanced. Lifting weights 2-3 times per week is exceedingly powerful way to maintain muscle bulk and fitness and helps deter osteoporosis. Pushing oneself to a limit in 3 sets and then resting the muscles for 2-3 days is what builds muscle. Work with a trainer until you understand how this can be done. Upper body strength is especially important to maintain in PWS. For great ideas and some of the science behind body building techniques (See Mark's Daily Apple online for tips for yourself that you can modify for your child's needs).

Behaviorally a person with PWS needs specific goals, incentive and possibly rewards to initiate and maintain an exercise program if it is not already part of your routine. He will undoubtedly need an exercise buddy to help him to stay on track and to share the experience. An MP3 player with an updated exercise playlist that is used only during exercise will help motivate and also maintain some novelty. Your child can work for rewards in the form of downloading new music.

## Charting and Reward Plan

Have a plan for charting. This includes, **who** will do the charting and roughly **when** in the day the charting will take place. Building the charting time right into your child's **schedule**. For example, as soon as he arrives from school, you will take down the chart and praise him for his cooperation in the AM and any reports that come from the school. Frequent behaviors e.g. whining which occurs multiple times per day, require frequent charting of "pleasant voice". Infrequent behaviors, e.g. fighting with a sibling several times per week, require daily charting of his success at "playing nicely".

This will help keep you, your family and your child on track. One option is to use paper charts for convenience and transfer data to computer for graphs and colorful displays to maintain everyone's interest. Negative comments will work against success. Comment on and chart only successes. Periods of failures are left blank.

If your plan includes stickers, stars or other small incentives to keep the child on track, keep these charting times in the schedule remind you to give this reinforcement.

See our handout on Behavior Plans.