



## Dietary & Exercise Management



### Food & health considerations for people with PWS.

Children with PWS are at higher risk of developing obesity due to two key characteristics of the syndrome. The hyperphagia (excessive eating) results in an increased energy intake while hypotonia (low muscle tone), often coupled with poor co-ordination, reduces their ability and desire to engage in exercise or physical activity. Consequently, energy expenditure is limited. Children consuming more energy than they expend can store the excess energy as fat.”<sup>1</sup>

#### Weight management and Prader-Willi Syndrome

- The research tells us that the body composition of children and young adults is different than the bodies of individuals with simple obesity”<sup>2</sup>
- Children with PWS need dietary controls in place to ensure that they do not over-eat and to maintain their energy intake to about 75% of the intake of children without PWS.
- A period of “failure to thrive” in young children, follows a period of excessive weight gain. the crossing of two centile channels e.g., from the 5th to the 25th percentile on the weight for length charts in a short period of time after 12 months and before 6 years.
- If uncontrolled, obesity would occur in 95% of PWS population
- Obesity usually found between the neck and knees, not all over the body.
- People with PWS can be very clever at finding food, and minimising access to the food is a constant challenge for carers.
- Even with a high IQ it is hard to achieve true independence due to food control problems.
- Young children cannot be obese without the help of parents and significant others. <sup>3</sup>

<sup>1</sup> Exercise and Physical Activities for Children By K Reid and P Davies ,University of Queensland ,Brisbane .2012

<sup>2</sup> Brambilla et al in The American Society for Clinical Nutrition May 1997

<sup>3</sup> (Urs Eiholzer, Switzerland, 2008)



## Dietary & Exercise Management (cont'd)

### Dietary Management Strategies

As mentioned people with PWS have an energy expenditure that is much lower than in the general population. General strategies to assist with dietary management include:

- Use the expertise of a dietician to present perfectly balanced meals at regular times spread out across the day and evening
- The daily routine should consist of food and drink 6 times a day
- Mealtimes scheduled at a set time each day as per the daily household routine
- Use smaller plates, make water available at all times, provide choices of fruit cut into slices
- Access to food out of meal time is not permitted
- The person with PWS should be involved in the menu selected from pre prepared menus, as suggested by the dietician. There will be no deviation from that menu
- If you are going to be eating out, plan/rehearse what can be ordered
- The carer will be responsible for serving the meal ie: not PWS person
- If carers /other family members are eating in the house they eat the same meals as the person with PWS. If they choose to eat other food they eat it outside the house.<sup>4</sup>

### Balancing Energy Intake with Energy Output

People with PWS have an energy expenditure that is much lower than in the general population. To lose weight, energy intake must be less than energy output. Exercise programs are as important as dietary management and regular exercise activities **MUST** be built into the daily routines.

It is also important to chart and review the effectiveness of the exercise in balancing the energy intake with energy expenditure. It may be beneficial to utilise the expertise of personal trainers and exercise physiologists to develop an effective exercise program.

How much energy a person expends is determined by 4 key factors:

- DURATION of the activity
- INTENSITY of the activity
- TYPE of activity
- METABOLIC EFFICIENCY of the person exercising.

### Remember:

Any exercise is better than none.



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