

# *Prader-Willi Syndrome and the Younger Child*

- an IPWSO booklet -



## FOREWORD

This little booklet is written in English by parents and Board members of the International Prader-Willi Syndrome Organisation. It can be freely downloaded from our website. It is not a medical directory, but has been written to help parents of newly diagnosed children (our “Medical Booklet”, also on our website, and already translated into several languages, can be downloaded from [www.ipwso.org](http://www.ipwso.org). You will also find more help and support on our website.) *Edited by Linda Thornton*

## BRIEF OVERVIEW OF PRADER-WILLI SYNDROME



**P**WS is a complex disorder. It occurs in all races and sexes. Swiss doctors Prader, Willi and Labhart published a study of floppy babies with certain characteristics in 1956. Following the usual practice of identification, the syndrome was named for the researchers. Research shows that it occurs in 1 in 15,000 to 30,000 live births and affects males and females equally; it is a genetic disorder and occurs randomly. It is not the ‘fault’ of either parent and it rarely recurs in the same family. A small piece of genetic information that is missing or non-functional on 15th chromosome is responsible for the characteristics that make up this syndrome. The most important symptom is the compulsion to overeat and that often occurs around the ages of two to four years (hyperphagia).

PWS has been described as a two stage syndrome. In the first or “failure

to thrive” stage, weight gain is slow and developmental milestones (both motor and language) are delayed. The baby tends to be “floppy” due to low muscle tone and has a poor ability to suck, leading to poor weight gain.

Without environmental controls, serious weight gain occurs in most children. As this second stage evolves, behaviours such as tantrums, stubbornness and mood change also may become evident. However, in describing a syndrome such as this it is important to point out that not all the characteristics are predominant in each child. Your child will be himself/herself first and foremost; some of the characteristic behaviours of the syndrome will occur, and some won’t. Careful and consistent management from parents, caregivers, and families will help lessen the extremes. IPWSO can offer support, guidance, and further information.



*Primary features of PWS include:*

### **Hypotonia**

Hypotonia is deficient muscle tone, and is seen in every newborn baby with PWS. The baby will have difficulty in breastfeeding or sucking from the nipple of a bottle, and may need to be tube-fed. Muscle tone improves over time with physiotherapy, exercise and growth. Treatment with Growth Hormone, if this is available in your country, is also helpful in compensating for hypotonia.

### **Hypogonadism**

Decreased size of the genitals and incomplete development of sexual characteristics at puberty are commonly seen in PWS. In boys, undescended testicles are common. Surgery or

hormones are used to help the testicles descend, and sex hormone therapy is effective in improving secondary sexual characteristics at puberty.

### **Developmental delays, cognitive dysfunction**

Although your baby may be slow to sit, crawl, walk, and talk... it will happen! On average, it takes about twice as long as in the general population. Your doctor or paediatrician should be able to advise a team approach to help your child reach his/her full potential – such as a physiotherapist, speech therapist and later a special preschool and individualized educational plan.



## EARLY INFANCY

### Birth to Six Months

Mothers consistently report little fetal movement. Births are sometimes breech, shoulder presentation or Caesarean section. Many newborns are pre-term or post-term, and they may have below-average birth weight. Because of weak muscle tone, babies with PWS may have difficulty moving, crying, feeding and staying awake. They're like sleepy little rag dolls with

a weak cry. Remember, despite the presence of these physical limitations, do not lose sight of the fact that your newborn is developing and needs stimulation and nurturing just as any infant - maybe more. And this phase of difficulties will pass with time.

### Feeding your Baby

Because of the weak muscle tone at birth, successful breast-feeding may

not be possible as babies may not obtain sufficient quantities of milk by nursing. While in hospital your baby may be tube-fed which is the easiest method of nourishment. When you leave hospital you may still be using this method for some weeks. You will be given support and training in how to use this method.

Your baby is unlikely to cry to be fed, so you may have to wake him/her for feeding times.

Don't force your baby to take all the formula - be guided by your paediatrician or nutritionist. Your baby's ability to suck will determine what method will work best until the muscle tone improves. Be patient with your baby. Try to massage the cheeks gently with your fingers to encourage swallowing but be careful not to choke the baby - swallowing may not be so easy for him/her.

It is important not to overfeed or underfeed your infant.

The biggest danger at this stage is not feeding the infant enough. Fat is extremely important for brain development and protection of vital organs and should not be restricted in the first months of life. Also, the hypotonic infant can use too much energy trying to suck. It's important to work closely with an expert (dietician, nutritionist, paediatrician, visiting nurse) during this period to monitor growth, feeding time and energy requirements. Your baby needs the correct nutrition to allow him/her to grow and at this stage, there is no proven relationship between feeding problems now,

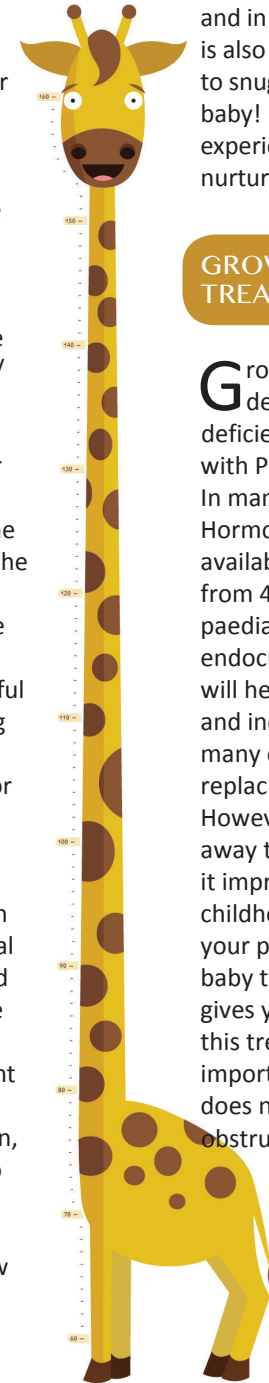
and in later life. Feeding time is also bonding time, so be sure to snuggle and cuddle your baby! This warm comforting experience provides positive nurturing for you and your baby.

## GROWTH HORMONE TREATMENT

Growth hormone is well demonstrated to be deficient in practically all those with PWS.

In many countries Growth Hormone Treatment (GHT) is available for your baby, often from 4 months (or when your paediatrician or paediatric endocrinologist advises). This will help strengthen the muscles and increase height. There are many other benefits of replacing growth hormone. However, GHT does not take away the hunger drive, nor does it improve behaviours in later childhood. It is important that your paediatrician gives your baby the correct dosage and gives you full information about this treatment. It is also important to be sure your baby does not have untreated severe obstruction (before starting GHT

Unfortunately, this treatment is not available in all countries.





**B**abies with PWS sleep a LOT! Although this is important because they tire easily, they should not be allowed to sleep 24 hours a day because all babies need stimulation to develop. You may find you need to wake your baby for feeding and stimulation, but you must also be alert to indications of him/her being overly tired. As muscle weakness diminishes, awake time will be longer and a stimulating environment will encourage responsiveness.

Most babies with PWS do not cry often or very loudly. By responding to your baby at any indication of pleasure or discomfort it will reinforce baby's efforts to express him/herself and will improve the quality of interaction with others. Physical contact is very important. Carry

your baby around when you can. Play, talk, sing, and read to your baby. Let your baby sleep in your lap.

Have your baby in a room with lots of activity, preferably in a crib with rungs so s/he can see what is happening when awake. Take your baby from room to room with you, take it outside when you hang out the washing, do the gardening, sit and watch the butterflies. Watch for head position; with weak muscles, the baby's head can often remain in one position too long. Change their position regularly. Even change the position of the cot or crib to help stimulate interest. Watch for sunburn! Infants burn very easily and babies with PWS often have a very fair skin.

Use an infant carrier with soft padded support for the head and take your baby with you so you can provide entertainment, new happenings, stimulation, and something to watch.

As your baby grows older, be alert to all efforts to reach developmental milestones and adapt the environment to encourage your baby to do this. All children develop in a fairly predictable sequence, although at different rates. Review "normal" development, not so you can tell 'how far behind' your baby happens to be, but so that you can recognise the skills being mastered on your child's own timetable.

Initially your child may lack muscle strength to reach for dangling objects. Place them close enough to be touched and grasped with little effort. Objects should be rewarding enough, for example a bell that rings, to encourage repeated efforts. Your child may use scooting or rolling as a substitute for crawling. Offer your child specific opportunities to explore until the motor skills improve. For example, place him/her in front of an open pot cupboard, or give a roll of toilet paper to unroll or box of tissues to undo; boxes of soft toys, and toys with different shapes. Exploration of new things and places is fundamental to reaching developmental milestones and exploring means "getting into things".

Remember your child will be developing according to his/her ability; slower development of milestones does not necessarily mean your child is more impaired than the average child with PWS. Milestones will be reached – don't force them, allow them to happen naturally.

### A VERY APPROXIMATE GUIDE

• Smiling	3-6 months
• Independent sitting	13 months
• Single words	21 months
• Walking	28 months
• Sentences	3.6 years

*Try not to compare your baby with others.*

### Speech and Language

Language is often delayed in children with PWS. You can help by responding to all efforts to communicate, be it a smile, a whine or a grimace. When your child starts making sounds, imitate them. Responding this way introduces new sounds as a game and the imitative and interactive process begins. This is how your child will begin to understand that communication is a way to interact... with you, and the surroundings.

It may be difficult to understand what your child is saying and difficult for your child to pronounce full words, so, as s/he becomes more mobile, get him/her to show you, or point to objects when you don't understand what they want. Some families have great success with sign language until the words start coming naturally.

Encourage the use of full sentences, repeat a mis-used or mis-pronounced word correctly and have them repeat this after you - if only one word results in communicating a need to you, then one word is probably all s/he will say.



## Pre-school

- Three to five year olds are usually walking, talking and lovable children whose needs are beginning to change. They will need encouragement to accomplish new gross motor skills.
- Try not to be overprotective; allow experimentation with new more difficult tasks and activities. Do this in a safe environment. Continue to create stimulation and encourage them to do things on their own. Do watch out for stairs, however, as good and confident balance is often a delayed development.
- Bruising - you may start to notice how easily your child bruises – this is quite common in PWS, even though there is no abnormality of blood clotting.
- Now is the time to try to encourage your child to walk more, rather than your carrying him/her; use dancing and music as a form of exercise.
- Set a good diet and follow it meticulously (see section on food), make sure others do also.

- Read to your child, introduce puzzles in all shapes and sizes. Above all, love and enjoy your child just as she/he is. Help your child to understand their special problems, but emphasise all the good qualities you find. Offer a sense of security and self-worth which will provide a background against which they can grow and learn.

At this point in your child's life, food concerns and behaviour may become more of a problem. This is the time to begin routines that will need to continue throughout his/ her life. Good routines established early will make for a much easier transition into the school years and beyond. Routines around food, sleeping, and what is and what isn't acceptable behaviour will actually help with learning patterns. Children enjoy routines and respond well with clear boundaries.



## SCHOOL YEARS



Children with PWS are usually very receptive to learning; they generally have good reading skills but poor numerical skills, and handwriting can be slow to develop. They show good ability to learn computer skills, and often have good fine motor skills (jigsaw puzzles, threading beads etc.). Their IQ level generally falls in the just below normal level but often shows “islands of competence”, in other words, they might be equal with their peers in some areas, but need support to reach potential in others.

Maths teaching needs to be conceptual and practical and often repeated many times before there is understanding. Once understanding has occurred, however, the concepts remain. Like all children, they thrive on praise and “little and often” is an excellent system. Teach your child how to use a calculator to work out simple sums.

### Support at School

Children with PWS need support throughout school, and respond particularly well with one-on-one help. When choosing a primary school for your child, make sure you visit the school before your child turns five, apprise the principal of your child's needs and hand over all appropriate information. If your country has a PWS Association, ask them to help you advocate for support.

### Positive instructions

Children with PWS tend to have a fairly rigid, or “concrete” way of thinking and tend to work best to a set routine and positive timetable. They can accept change if prepared for it beforehand, but a sudden unexpected change may result in non-cooperation - generally this is more so with the older child. It is sensible preparation to warn beforehand if something is to be postponed or cancelled. If the child doesn't clearly understand the instructions, you may find resistance to change. A common indicator of this might be persistent or repetitive questioning from the child in spite of having heard the answer.

Be patient; use visual as well as verbal instructions.

Within an ordinary classroom, children with PWS may have difficulty in settling



and can become easily distracted. It is not 'naughty' behaviour, just part of the syndrome. They may work better with their 'own' desk and chair rather than being continually moved around.

Simple behaviour modification techniques such as 'ignore, redirect, praise' work well. Or removal from a situation which appears to be heating up, and redirection to another task until the person has calmed down. But basically, with the younger person with PWS, the behaviours which you will find in the classroom will be comparable to any child of his/her age. Try not to argue with them as this only creates a stubborn response. Be empathetic to their needs, slow down your instructions, repeat them when necessary and praise the child's attempts to follow. If a task seems insurmountable, break it down into easy components, taking enough time to complete each one.



### **Tiredness**

Young children often become easily tired and may fall asleep in the classroom. It is appropriate to ignore this rather than encourage 'attention at all times'. It is part of the characteristics of PWS and not usually a problem.

### **Sociability**

Children with PWS are sociable and interactive with other children but often tend to mix with younger children rather than their peers whose natural physical ability will often leave the child with PWS behind.

### **Physical Education**

Physically, because they have poor muscle tone, their ability to learn



sports, ball skills, skipping, etc. can be slower than normal - but they should be encouraged slowly and at their own pace. Their own peers should be encouraged to help and support them in a 'buddy' system when appropriate. To over-encourage something they know they cannot physically do, will only end in their ceasing to try. Growth hormone treatment will increase muscle strength and enable your child to accomplish physical tasks more easily.

### **Eating behaviours at school**

The major difference between the child with PWS and others is that because of the missing information in chromosome 15 which governs the appetite, there is no ability to control the intake of food. S/he may continue eating far past the

level of other children. Because of this, all care must be taken to ensure the well-being and safety of your child. This will require you to make sure that all teaching staff are aware of your child's needs.

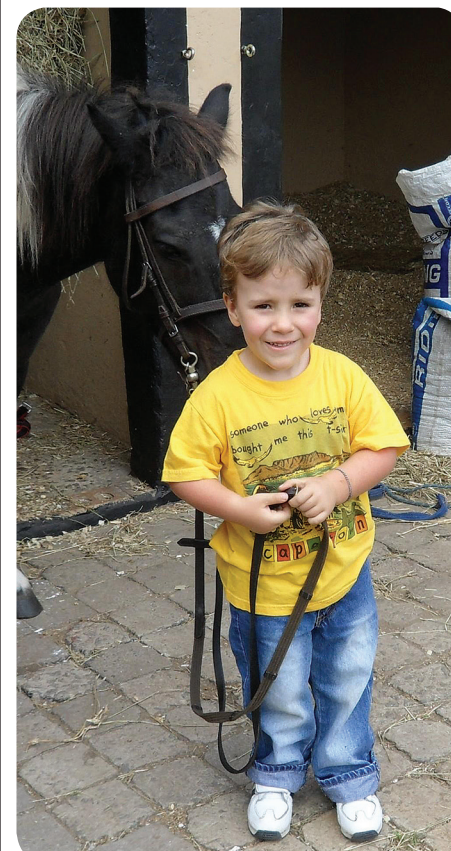
### **Practical Intervention**

This will entail some practical intervention from teaching staff and it will mean that lunchtime and playtime are supervised so that the child eats only what is prepared for play-time or lunch-time (otherwise everything may be eaten at once), and that other children are not passing unwanted food to the child, and that the child him/herself is not suggesting to other children they finish their lunch for them. This is of ultimate importance. Children in the classroom must be told not to give food to this classmate; they need to be told in simple and easily understood language along the lines that it is a danger to the child's health, just as some foods are dangerous to other children with allergies or diabetes. Food discarded in rubbish-bins in the classroom will need to be removed so that it does not provide temptation. Lunch-boxes may need to be placed in view of the teacher so that they also do not provide temptation, or kept in lockers out of reach and handed out each lunch-break.

It is not sensible to put a child with PWS on any duties involving food (such as lunch monitor, fetching or distributing school lunches, etc). Quite simply, it is not a good idea to put any child into a situation where they will likely fail. It puts the teacher/child trust in jeopardy and does nothing for the self-confidence of the child.

In situations where cooking is taught at school, teacher-aid time should be allocated to the child with PWS for safety and precaution reasons. For most schools this will not be a major problem and teaching staff are usually willing to cooperate at each stage.

Children with PWS are no different from any other child with special needs in that their uniqueness needs to be recognised and catered for. At a primary level, there should be few obstacles that cannot be overcome. On a general level, these are pleasing, happy, friendly children with an outgoing personality.





## AVOIDING OBESITY IN YOUR CHILD

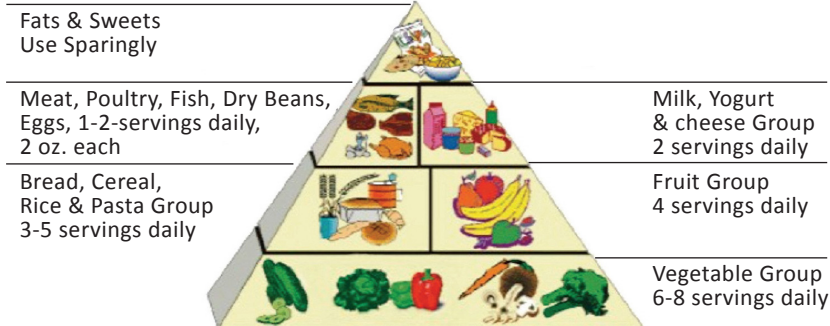


As the muscle tone begins to improve in your child, so too does the appetite. Whereas once it took you hours to get this tiny baby to take a tiny amount of formula, it seems unbelievable that you will have to work even harder to keep food away from him/her. Remember that this is a major part of the syndrome; think of it as the on/off switch for appetite control not working as well as it should.

Generally sometime between the ages of 18 months and 6 years, feeding difficulties are replaced by an apparent obsession with food and compulsive eating. The good news is that the weight

gain can be controlled. And for the sake of your child's health, this is now essential. Obesity can lead to many severe medical complications such as diabetes, heart and circulatory problems, breathing problems, skin breakdown, and joint problems.

You will need the help of a professional nutritionist or dietician. Ask your doctor to recommend someone who is familiar with PWS. If the professional is unfamiliar with the syndrome, enlist the help of the PWS Association or online resources in providing information and data on diet and calories required.



The caloric intake of a child with PWS is very different from that of a normal peer. Weight gain can occur rapidly on considerably fewer calories than for the average child. Generally speaking, a child (not a baby) or adult with PWS should be eating only 75% of his/her peers' intake. Growth hormone treatment allows this to be a bit more liberal.

It is important that you recognise that obesity will be a problem and take steps to control overeating before it becomes a life-threatening situation. For a person with PWS, the drive to eat is always there.

No matter what might be said about the person with PWS, or what the person with PWS might say, this is not an area that we can expect them to take control: it's just not possible. A dietician acquainted with the syndrome can establish the correct number of calories your child needs to consume to maintain a normal rate of weight gain, or to lose weight while still supporting the rate of growth. Your child needs proteins, vitamins and minerals. Food intake must reflect careful planning to include these nutrients.

It is important that food management starts early. It is far easier to start outright than to remove privileges later because of weight gain. Naturally, you

do not need to start "locking up the supply" until necessary, but there is nothing wrong with serving food from the kitchen rather than the family table, not leaving food around and clearing the plates and scraps from the table once the meal is finished.

Knowing what to feed your child is only the tip of the iceberg. Most children with PWS become incredibly quick and clever at getting food. Your job of limiting access to food is a big one - but it is worth it. Your child will be healthier, look better, feel better, move better, be more acceptable to others, and will generally be happier.

### Managing Food Intake

Counting calories is one way of monitoring food intake. But equally, if not more important, is to look at FAT and SUGAR content. It takes only a moment to read the food labels at the super-market and see the percentage of fat in each product. Avoid foods with high fat or sugar content. Be careful when reading labels not to be tricked into thinking "Lite" must mean it is good for you, or that "Sugar-free" means low calorie. A product that advertises itself as being "97% fat-free" often has high sugar content.

When giving your child a snack, make it a piece of fruit and a glass of low-fat milk or perhaps low-fat cracker with cucumber or tomato. No more potato crisps, tacos, biscuits made with butter, or any high-fat snack; these are wasted calories which only make the child quickly feel more hungry.

*Use these ideas when the time is right for your child:*

- carefully control portion size
- limit access to food - inside the home and out
- weigh regularly to monitor weight gain and determine the appropriateness of the fat intake
- know the caloric values and fat/sugar values of food to allow flexibility in planning menus and the variety of food
- incorporate exercise into your growing child's daily activities

- clear food from the table immediately after a meal
- avoid leaving sweets, fruit bowls or other accessible food around
- serve food from the stove instead of the table - no second helpings for anyone
- everyone who comes in contact with your child needs to know what s/he can and cannot eat
- encourage family members to limit eating to designated meal times and snack times (this may mean some snacking when the child is in bed, or out of sight and earshot!)
- control intake of the low calorie foods too, since large quantities add up ( such as fruit)
- if you don't have a lockable pantry, consider turning the broom cupboard into one
- use combination locks rather than keys which can get lost and/or used by the wrong person!



## MEDICAL HELP

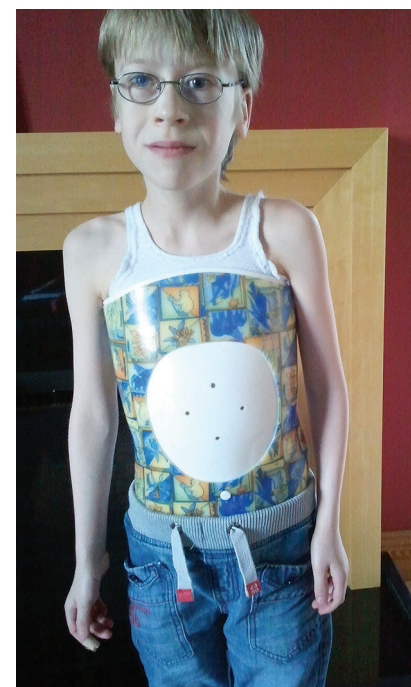
*Although Prader-Willi syndrome is not curable, there are some medical interventions that may be helpful.*

**T**hrough your PWS Association, the International PWS Organisation, or the Internet, there is much written and published material to help inform your child's doctor about care of the child with PWS. However, it is important that you also be aware of potential problems and treatment, since most doctors are not familiar with PWS.

*These are just a few of the treatments that are used in children and adults with PWS*

### Growth Hormone Treatment

The most successful is Growth Hormone Treatment. Over the past 10 - 20 and more years, research has shown that most people with PWS have insufficient growth hormone, and Growth Hormone Treatment can help children with PWS develop a more normal body composition with normal muscle size and strength and a greater chance to reach their expected natural height. To access this treatment, you must go through your medical care provider, who will guide you through the various tests and measurements that need to be undertaken. It is important to do a sleep study to assess for obstructive sleep apnea (pauses in breathing) before starting treatment, and have it treated, if present. Growth hormone treatment is not available in all countries, but children can grow and develop strength through other methods, such as physiotherapy and exercise.





## Testosterone

Treatment is given to boys at or after the time of puberty to help development of sexual organs, facial hair, deepening of voice, and a more masculine appearance. It is recommended that parents consult with their endocrinologist to ascertain benefits.



## Estrogen

Estrogen is given to girls as they approach puberty to increase likelihood of menstruation and improve bone density. Again, it is recommended parents talk to an endocrinologist or their health-care provider regarding the benefits to their daughter.

Arrange an appointment with your doctor to discuss this more fully when the time comes.

## BEHAVIOUR MANAGEMENT

Infants and young children have very pleasant, outgoing, cooperative temperaments. But stubbornness and tantrums may emerge around age 5 onwards. Emotional outbursts tend to occur over very minor issues and appear hard for the child to control. Managing these behaviours becomes a major focus for parents and other caregivers.

First of all, your child with PWS needs the same kinds of limits and boundaries you would establish for any other child. And they need to be enforced consistently.

From the beginning, set the rules and stick to them! Consistency is important for any child. A basic set of rules and expectations can serve as a foundation to build your child's sense of security. Your child will thrive on routine and predictability. When changes are necessary, prepare him/her ahead of time. Don't make promises that you can't keep. Children with PWS do not

forget! Other children may pout if a plan is changed; yours may dwell endlessly and repetitiously.

Routine is necessary. Pre-planning trips to grocery stores and restaurants stand a good chance of eliminating a tantrum in public (*Examples: Set the rules before you go: "if we go into this grocery store we will buy only groceries for the house. I am not going in here to buy you presents or goodies. If you perform or make a scene, I will simply leave the grocery store and we will go home, is that ok?" or: "We are going to this restaurant as a special treat. Once we are in, I will look at the menu and help you choose. If you don't like the choice, then we will go home without having a meal here. "Do you understand? Can you tell me what we're going to do if things go wrong?"*)

Allow and encourage your child to do everything possible for him/herself and expect from your child all that s/he

is capable of doing. Don't excuse your child from helping out around the house, you expect contribution from your other children, so you should from the one with PWS. Making the tasks simple so that they can complete them is giving them a sense of self-confidence and self-esteem. They also like to please and show that they can accomplish things too.

Many, although not all, outbursts are related to eating and food; family members should enjoy their treats in private and keep them inaccessible. Pre-plan how to manage the many food-related events the family may attend. Teach carrot sticks instead of biscuits or other sweets for treats and snacks. Reinforce this message with friends and

family and ask them if they could, as far as possible, support you by sticking to your healthy-food regime. It is tough on you if friends helpfully tell your child with PWS to "ask Mummy or Daddy if you can have an ice-cream". You will need to train your friends as well as your family.

When the upsets come, trying to talk it out does not help, but only seems to increase the upset. Don't give in to the demand in order to stop the behaviour, this only reinforces the fact that having a tantrum works. Use "time out" (bedroom or someplace quiet) until the episode is over. Then forget it. Dealing with outbursts can be exhausting, so give yourself credit and take a break as needed.



## GRANDPARENTS, NEIGHBOURS AND THE REST OF THE WORLD

*"Just one piece won't hurt!"*

*"If you fed that child right, she wouldn't be hungry!"*

*"There're no calories in that!"*

*"It's only fruit juice, it's good for him!"*

Although there is an inherent belief from grandparents that they are not spoiling their grandchildren, for the one with PWS, they surely are! They're not just spoiling the child, but all the time and hard work that you have put into this special grandchild. Most grandparents will cooperate because they truly care, but remember that they're having a hard time too in understanding and accepting this strange "syndrome".

Start out with the facts and repeat them as much as necessary and with as

much patience as you can muster. Give them brochures, help them understand the medical terminology. If the message is still not getting across, ask, *"if this child was a drug addict, or an alcoholic, you wouldn't be giving him drugs, or a drink, now would you? You are endangering his health and his life. Right? Well, the same goes for PWS!"*

If all else fails, tell grandparents that if they will not help you maintain your child's diet, you will not be able to visit them as much. You make the rules, remember? And stick to them.

NEIGHBOURS: handing a visiting child a treat or a drink is commonplace in our society. If your child sees the neighbours as a source of food, s/he will become very much a nuisance in

the neighbourhood. You will need to visit the neighbours, brochure in hand, explain PWS and ask that they refuse requests for food and never offer any. Leave a copy of this booklet.

The rest of the world: Them too. Your skills in explaining PWS will only improve as the boundaries of your child's world increase. Everyone who comes in contact with your child will need to know the golden rule: Don't feed this Child!

**SIBLINGS:** What you tell brothers and sisters of your child depends on their age - a little like sex education. The two-year old won't question. The three to four year old will observe and may wonder why it is so hard to feed baby or why baby is maybe different from a friend's baby. The five year old is likely to be aware that there is a problem and of course, six year olds and up know for sure something is wrong.

For example if the three or four year old asks why baby has to go to a physical therapist, you can tell him that the baby was born with weak muscles that make it hard for her to lift her head and that the therapist can help her get stronger.

The older child might go further and ask why baby's muscles are weak and you can tell her that you don't know exactly why but something went wrong while the baby was growing in mummy before he was born.

Siblings will hear adults talking about Prader-Willi syndrome and when they are ready, will ask about it. Tell them truthfully and on a level that they can understand. There may be a lot of questions, or just a few, but the first important thing is to give a message to



your other children that this is something that they can ask about, even gripe about at times, and that you are willing to discuss with, and listen to, them.

The second important thing is that you do discuss it with your other children by the time the child with PWS begins to forage for food. If siblings understand about the syndrome, they may be more willing to put up and help with all the limitations on treats, food accessibility, etc. that it takes to control food intake.

Expect your other child(ren) to be jealous of the extra time and attention your child with PWS requires. And don't expect them to always understand these needs - see to it that the siblings have their fair share of parents' time too. Make sure they have their own 'special treats', perhaps time alone with grandparents, parents, or other outings. Try to obtain some care for your child with PWS from outside the family (such as Respite Care) so that the rest of the family can all have a break.

## REMEMBER YOUR OWN NEEDS



Please remember that you are a special person too. Be kind to yourself; watch out for burnout.

Danger signs: exhaustion...cynicism... less efficient... taking longer to complete the same task... feeling indispensable ... excessive number of hours devoted to caring for others... instantaneous irritation... quickness to anger... taking more risks... feeling imprisoned... increased use of tranquilizers, alcohol, cigarettes etc... insomnia, headaches, ulcers, worry... feeling guilty.

- You cannot give 100% of the time and still have anything left for yourself.
- You can be angry and share frustrations with friends.
- You need time alone or just with your partner.
- You need time off from being a caregiver without feeling guilty.
- At times, it is normal to feel that you cannot cope with life.
- Continue to do things and go places you enjoy.
- Take care of yourself and your partner. Keep in mind that you have a spouse/partner, family, friends, interests, maybe a job, other children. All those parts of your life were there before your child with PWS – they are still there. They need you and you need them.

As you go through the grieving process for the normal baby that didn't happen and for the hope that the problem was temporary or curable, you may find that you and your partner are grieving differently. Often the father may withdraw into work, respond with anger, and refuse to talk about it, or say practical things like, "We'll just have to accept it since we can't do anything about it". The mother may be tearful and emotional and think him unfeeling. Occasionally, these roles may be reversed. It is essential that each understand that both are grieving, but at different rates and in different ways. Seek professional help if it starts to undermine your relationship.

Try not to look ahead - not ten years, or ten months, or even one month. Worrying about what the future will bring will not help your child, your state of mind, or your present life. Go day by day.

None of us knows what tomorrow may bring. The outcome and quality of life for people with PWS is very different and much improved today from 20 or even 10 years ago, and it will be better still in the future. There is much research taking place on understanding the biology of PWS and developing improved treatments. Try to keep up to date through PWS newsletters and conferences, where available. And avoid dwelling on the poorer outcomes of the past.

As it is your goal to help your child, make it your goal to find some happiness in each day.





[www.ipwso.org](http://www.ipwso.org)

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to IPWSO through our website.*

*Thankyou!*

