

Prader-Willi Syndrome

Behavioral challenges in the first years
and how to cope

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The presentation

- Our reaction. When we have the child. Risks for the child
- What we see concerning behavior during the first years in PWS
- What to be aware of, differences to expected behavior
- How to stimulate the child and respect the child's needs
- Teaching the child good habits from early years, so life becomes easier

My intention.

- With this presentation my focus is the needs of the young child and the family.
- When knowing your child with PWS you can do a lot to help the child to be part of society, enjoy activities, and behavioral challenges can be minimized, also the first years.
- Personal experience:
Information about PWS to all he met and meets is so important.
It has always been a big help to him and to us (parents and brother).
Written information helps, then all contacts can understand and help

A great risk can be:

- The parents are shocked, that the child has PWS and is not the child expected
- Some parents dare not be with the child, do not want contact to the child
- Some are disappointed that the child does not react to their contact as expected

- Parents wants to know: what is the future?
- Parents search for knowledge about treatment and a cure
- Some parents spend more time on the internet than together with the child

- The child is silent, is fed, but has little personal contact and does not receive the important needed stimulation

Characteristics of the first years

- Like other children the child undergoes great development
- But there are differences to what is usually seen

The child: the first weeks to months

- The newborn child is floppy, hypotonic, like a child born 10 weeks too early
- Not interested in eating, has difficulties sucking and swallowing, tube feeding needed
- No cries, not asking for attention: seen as a very silent and “easy child”
- The first weeks and months the child’s motor and eating capacities are very much as you see in a premature child, and the child’s motor milestones are delayed

After the first months

- Moving and motor activities develop: more strength in legs and arms
- Head control better. Enjoys being moved, physiotherapy, motor stimulation
- Gradually contact and attention become more intense.
- Your child, responds to sounds, the child's sounds become more distinct
- Enjoys music and singing
- Smiles to you, looks at pictures , is more visually alert
- Eating becomes easier, tube feeding stops, but eats slowly, risks for aspiration

At age 1 year:

- Motor: can sit , crawling is next step
- Language: many sounds, perhaps few words
- Eating: slowly but easier. Looks at food, does not search (most often)
- Some fall asleep when eating - it is not epilepsy
- Sleeping: most often Ok, some wake up often

Behavior:

- Not demanding, but enjoys contact, singing, music, being danced with
- Activities: can sit alone, looking at toys, lifting toys, babble, can be repetitive .
- Some react to changes in daily rhythm, but most often not at this age

1-2 years old

- Motor development goes fine: crawling, standing, walking with support
- Big differences in motor abilities : and motor abilities do not reflect cognition!
- Language: more words, more understanding
- Play: can have favorite toys, can be persistent sitting with the same. Needs shifts
- Daily program: Learn the rhythm, but can cope with changes, or does not notice

- Contact: enjoys, but does often not ask for contact. Enjoys other children, but cannot follow (motor) . Some avoid small children , prefer adults or older children
- Eating easier: enjoys cakes (if served) put on weight, attention grandparents!
- The golden age: big progress , normal weight, the easy smiling child

2-3 years

- Motor development: differences, but progress, many start to walk
- Language: more words, can follow pictures in a book
- Understanding: better, do things when asked
- Play: food items can become favorite, (I pad, toys). Can be repetitive
- Contact to other children:
- Can enjoy , can participate in role plays , can have a role, but often needs guiding.
Follow the others. It can be difficult to accept changes in the play.
- Food in the room: can be distracting
- Access to kitchen : best supervised
- Prefer the same routines.
- The age to learn all the good habits for the rest of the life

What can we do for the child

- Inform all in contact with the child about PWS:
- Grandparents, siblings, neighbors , colleagues etc.
- Grandparents feel sorrow: need to know that their time for the child and support is important: playing with the child, not serving cakes
- Siblings: Tell them it is not their fault
- Be sure to spend time with siblings alone if possible
- Friends and others: teach them how to help you, if needed. They can spend time with the child, help with shopping, cleaning. An evening free for you.
- All contacts will stimulate the child 's development, and include the child in society. And all need to be informed about the child's diet plans

How to plan for the child's development

- Food: Have a plan for meals that are followed. Also at visits.
Tell all around that the child's condition demands a plan for the food.
Especially grandparents need "clear rules"
Then the child will hear and learn from early on.
- Meals at parties:
- The child leaves the table when he/she has eaten what is served.
- Sitting looking and asking for more is bad care
- Moving: Have a plan for daily motor activities. From doctor or physiotherapist
- Cognition: Talking, singing songs, reading books. Illustrations. Toys easy to handle
- Language: Be aware of what is understood, and how. Give time for answers
- Sleep: Create good habits

How to help the child

- Be concrete. Use drawings and signs.
- Have a white board or similar with drawing: what is planned
- No irony
- No maybes
- Secure time enough for talking, answering. Keep focus
- With other children:
 - Include the child. Create games where the child can participate and contribute.

Hygiene. Why to mention that now.

- We know that hygiene can be a big problem in older children and adults if clear rules are not “incorporated” from very early:
- Like other small children the youngest do not understand why, but learn
- Washing hands before and after each meal. After toilet visits
- Teeth brushing 2-3 times per day
- Fixed rules for changing and washing clothes. Illustrate, use a white board.
- Which clothes and shoes for which weather and temperature and occasion

Thank you so much.

Questions after next presentation

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