



What Parents Want Professionals to Know

When Giving a Diagnosis of Prader-Willi Syndrome

Early Diagnosis and Later Diagnosis Guidelines

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Parent of a son with PWS



The Early Diagnosis Experience

What Parents Want Professionals to Know

Long before our baby was born
we dreamt of his or her life
and fantasized various futures

None of these dreams included
a rare genetic disorder called
Prader-Willi syndrome

The Early Diagnosis Experience

What Parents Want Professionals to Know

The first hint that something is wrong with our precious baby we experience a multitude of feelings:



- Confusion
- Fear
- Terror
- Shock
- Helplessness
- Anger
- Punished
- Defeated
- Exhaustion
- Alone

The Early Diagnosis Experience

What Parents Want Professionals to Know

- When specialists are brought in, our fear and panic increase exponentially.
- **From the moment you first encounter a parent, you influence our feelings and attitude.**
- **Where you tell us, what you tell us, and how you tell us about our child's diagnosis of Prader-Willi syndrome will remain with us the rest of our lives.**

The Early Diagnosis Experience

When you speak with parents about Prader-Willi syndrome:

You have the power to instill despair or inspire hope and empowerment.



**Please strive
to inspire hope**

The Early Diagnosis Experience

What Parents Want Professionals to Know

When giving me the diagnosis:

- Speak with me in person.
- Don't deliver bad news on the phone.
- Please pronounce the syndrome correctly:
PRAH-der WILL-ee
- Please use person-first language:
“Your baby has PWS”; “People with PWS”; “People who have PWS”



The Early Diagnosis Experience

What Parents Want Professionals to Know (con't)

- I may be in shock when you tell me my baby has a serious medical disorder.
- I may not remember details of what you tell me... unless they scare me and then I may never be able to let go of that image.



The Early Diagnosis Experience

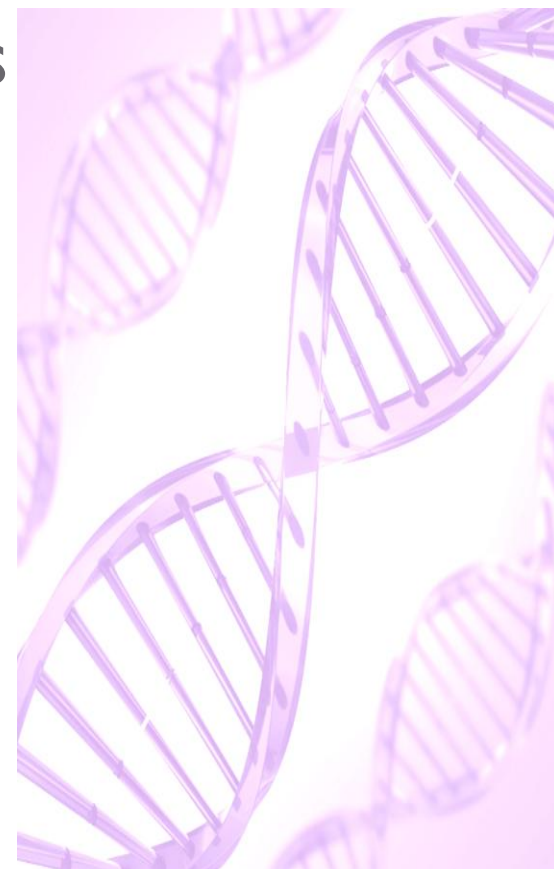
What Parents Want Professionals to Know (con't)

- Give me *factually current* printed material from the national **Prader-Willi Syndrome Association (USA)** website www.pwsausa.org and their phone number **800-926-4797** or
- **Prader-Willi California Foundation**
310-372-5053 www.pwcf.org
- Use *current* information and research to answer my questions. PWSA (USA) and PWCF are good resources.
- Schedule a follow-up meeting so that I may ask you questions I didn't think to ask during the first meeting or I don't remember you answering.

The Early Diagnosis Experience

When you give parents the PWS diagnosis:

- Tell me about the genetics of my baby's disorder in words I can understand.
- Don't talk at me or over my head.
- Don't try to tell me every genetic fact about PWS, just the highlights.



The Early Diagnosis Experience

When you give parents the PWS diagnosis (con't):

Things that are helpful for me to know right away are:

- PWS is a genetic disorder but generally not inherited. Tell me I can receive genetic testing if I consider having more children.
- PWS is a spectrum disorder; not everyone has all of the symptoms, and symptoms vary from person to person. This gives me hope.

The Early Diagnosis Experience

When you give parents the PWS diagnosis (con't):

- Tell me that PWS is a part of the human condition and is most often a random genetic event.
- Tell me there's nothing I or my spouse did or didn't do to cause our child to have PWS.



The Early Diagnosis Experience

When you give parents the PWS diagnosis (con't):

- Tell me that because my child has an early diagnosis I will be able to address and reduce many of the typical symptoms.
- This gives me hope and empowerment.



The Early Diagnosis Experience

When you give parents the PWS diagnosis (con't):

- Tell me my baby is born in a New Generation of PWS where we know much more about symptom management.



The Early Diagnosis Experience

When you give parents the PWS diagnosis (con't):

- Tell me I am fortunate to have an early diagnosis so that I may address my baby's symptoms early.
- Tell me that knowing the diagnosis will provide me a framework and a path.



The Early Diagnosis Experience

When you give parents the PWS diagnosis (con't):

- Tell me only the **FACTS**.
- Do not predict my child's future because you don't know it.
- Do not tell me that my child will be fat or obese or mentally retarded because this is **NOT** my child's *fate*.



The Early Diagnosis Experience

When you give parents the PWS diagnosis (con't):

- Inform me of the phase aspect of PWS: difficulty feeding, weaker muscle tone, metabolic problems, difficulty managing behavior, hyperphagia.
- Tell me that the more informed I am about symptom management the healthier my child and my whole family will be.
- Reassure me that supports *are* available.



The Early Diagnosis Experience

When you give parents the PWS diagnosis (con't):

- Tell me there are medicines, therapies, and interventions that will help my child grow and develop into a healthy individual.
- Tell me specifically about the benefits of growth hormone therapy.
- Tell me there are parents who can mentor me, guide me, help me understand the things I need to know.



The Early Diagnosis Experience

When you give parents the PWS diagnosis (con't):

- Tell me that PWS is one small piece of who my baby is, that he has many genes and is much more than just “PWS.”
- Tell me there is a great deal of research being done in many symptom areas including the hyperphagia symptom.
- Tell me that there *are* people with PWS who are bright, tall, healthy weight, well behaved, happy, healthy, and productive.



The Early Diagnosis Experience

When you give parents the PWS diagnosis (con't):

- Discourage me from surfing the net because the very difficult cases are generally highlighted there and don't necessarily reflect *my* baby's future.
- Encourage me to call PWUSA (USA) as soon as I can so that they may provide me with important information and ongoing support resources.

<http://www.pwsa-usa.org>

The Early Diagnosis Experience

When you give parents the PWS diagnosis (con't):

- Don't tell me, "God only gives us what we can handle" or "God chose me to be this child's parent because He knew I could handle it."

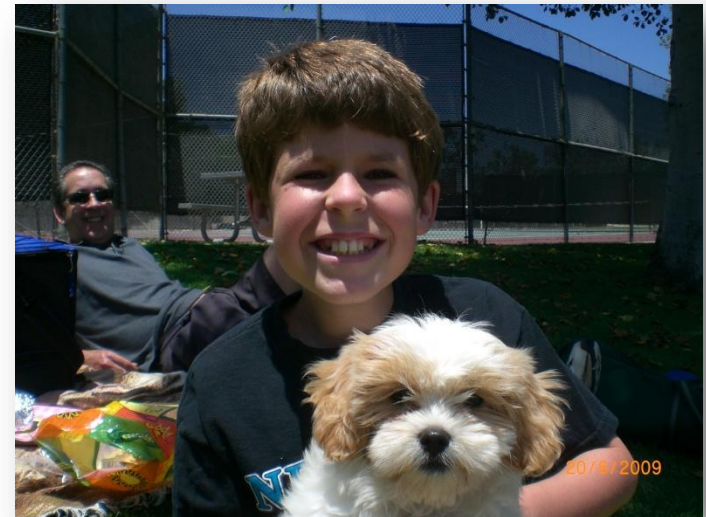


- Right now I may be cursing God or questioning my ability to parent my child.

You Need to Know That...

As the parent of a child diagnosed at birth or shortly thereafter:

- I need to feel like I have supports available
- I need to feel hopeful about my child's future
- I need to feel empowered so that I have the strength I need to persevere and advocate successfully for my child
- **I need to know I am not alone on this journey. Ever.**





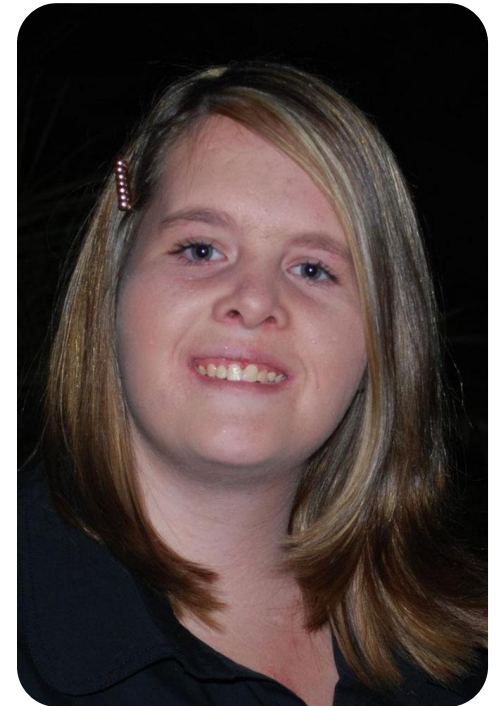
The Later Diagnosis Experience

The Later Diagnosis Experience

When you give parents the PWS diagnosis:

Most of what I need now is what you would have told me earlier, especially:

- Speak with me in person. Don't deliver bad news on the phone.
- Know that I may be in shock and may not remember what you tell me in the first meeting, so please schedule a follow-up meeting.



The Later Diagnosis Experience

When you give parents the PWS diagnosis (con't):

- Provide me with *factually current* printed information from either PWSA (USA) or Prader-Willi California Foundation
- Connect me with PWSA (USA)
800-926-4797
- Connect me with PWCF 310-372-5053
- Don't talk over my head. Use language I can understand.



The Later Diagnosis Experience

When you give parents the PWS diagnosis (con't):

- Tell me only the facts. Don't predict my child's future even if you think you know it... because you *don't* know *my* child's future.



The Later Diagnosis Experience

When you give parents the PWS diagnosis (con't):

- Tell me what nutritional phase my child may be in or entering and how I may prepare for that phase.
- Encourage me to contact PWSA (USA) as soon as possible so that they may provide me with important information and support.



The Later Diagnosis Experience

When you give parents the PWS diagnosis (con't):

In addition...

- Let me know you understand my life has been difficult.
- Tell me, “I know you've been struggling for awhile with your child's weight and/or behavior.”
- Reassure me that, “Having a diagnosis now will help you get the resources your child and your family need.”

The Later Diagnosis Experience

When you give parents the PWS diagnosis (con't):

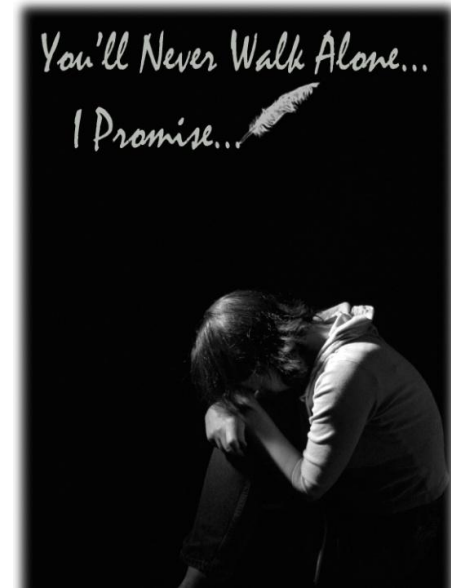
Affirm my feelings of:

- Validation – because I *knew* something was wrong and no one would believe me
- Relief – that I now have a direction for treatment and interventions for my child
- Anger – at not having a diagnosis long before
- Resentment – that I have been shamefully blamed for my child's spiraling weight gain and behavior problems
- Sadness – that my child could have benefited from therapies long ago

The Later Diagnosis Experience

When you give parents the PWS diagnosis (con't):

- Give me hope for a better future:
- Tell me that knowing the diagnosis will provide me a better framework and path.
- Tell me that there are medications, therapies, and specific PWS behavioral strategies that will help.
- Reassure me that supports *are* available and that **I no longer need to feel alone. Ever.**





Parents Want You to Know

Parents Want You to Know

- Given the right supports, our children and adults with PWS are loving, friendly, outgoing, talented, funny, bright, articulate, generous, brave, amazing human beings.



- Our kids are actors
- Our kids are authors
- Our kids are musicians
- Our kids are athletes
- Our kids are graduates
- Our kids are employees
- Our kids are beautiful
- Our kids are loved

Parents Want You to Know

- Absolutely having a child with PWS challenges us as parents. We need support.
- We need research breakthroughs.
- Having a child with PWS can broaden us into being more loving, compassionate people.



Parents Want You to Know

- What, where, and how you share information about our child's PWS diagnosis profoundly impacts us for the rest of our lives.
- You have the ability to start us off on a more hopeful attitude so that we pursue the support we need.
- We depend upon you to instill that hope.



Parents Will Be Forever Grateful for Your Continued Research of PWS and Your Compassion

