pwcf.org Prader-Willi California Foundation
Supporting People with Prader-Willi Syndrome

Prader-Willi Syndrome: The Later Diagnosis Experience

What Parents Want Professionals to Know

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Long before our child 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 first hint that something is wrong with our precious baby we experienced a multitude of feelings:

- Confusion
- Fear
- Terror
- Shock
- Helplessness

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.

When you present parents with the diagnosis of Prader-Willi syndrome 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.

When giving me the diagnosis:
Speak with me in person.
Don't deliver bad news on the phone.
Pronounce the syndrome correctly: PRAH-der WILL-ee
Please use person-first language: "Your child has PWS"; "People with PWS"; "People who have PWS"

Know that I may be in shock and 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.
Schedule a follow-up meeting so that I may ask the questions I didn't think to ask during the first meeting or I don't remember you answering.

Give me *current* printed material from the **Prader-Willi California Foundation's** website www.pwcf.org and the national **Prader-Willi Syndrome Association (USA)'s** website www.pwsausa.org.
Encourage me to call PWCF 310-372-5053 and PWSA 800-926-4797 as soon as I can so that they may provide me with important, accurate information and ongoing support resources. Provide me with their numbers.

Tell me about the genetics of my child'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.

Things that are helpful for me to know right away are:
PWS is a genetic disorder but generally not inherited, and that I can receive genetic testing if I consider having more children.
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.
Tell me that PWS is a spectrum disorder; not everyone has all of the symptoms, and symptoms vary from person to person.
Tell me that because my child now has a correct diagnosis I will be able to address and reduce many of the typical symptoms.
This gives me hope.

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 what nutritional phase my child may be in or entering and how I may prepare for that phase.
This gives me hope and empowerment.

Tell me there are parents who can mentor me, guide me, help me understand the things I need to know.
Reassure me that supports *are* available.

Tell me there is a great deal of research being done in many symptom areas including the hyperphagia and behavioral symptoms.

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.

Let me know you understand my life has been difficult.
Tell me you know I have been struggling with my child's weight and behavior.
Tell me that having a diagnosis now will provide me with a better framework and path and help me get the resources my child and my family need.

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

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.

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

Parents want you to know that absolutely having a child with PWS challenges us as parents.
We need support.
We need research breakthroughs.
We also need to know that having a child with PWS can broaden us into being more loving, compassionate people.

We need to know we are no longer alone on this journey. Ever.

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