

USA

PRADER-WILLI SYNDROME ASSOCIATION
Still hungry for a cure.

A Parent Journal

Dear Parent:

Although not required, we recommend including in your application a brief parent journal describing your child's first 18 years. Remember, you are trying to give a vivid picture to Social Security of how Prader-Willi syndrome affects your child's life. Some elements to include are:

- When was your child first diagnosed and how?
- Give an overview of your child's life related to the disability in each stage of life. How did it impact your child at school? Medically? At home? In the community?
- If your child has attempted to work, why was that attempt unsuccessful or difficult?
- If your child ever participated in, or sought, specific employment training - describe what worked well and what didn't.
- Provide a list of cognitive impairments (IW, auditory processing challenges, etc.) and give examples from daily life.
- Provide a list of behavioral problems and give examples from daily life.
- Describe your child's social interactions. What kind of social life does your child have? How does PWS make your child more isolated?
- List your child's daily living activities (bathing, brushing teeth, getting dressed, and preparing meals) and explain in detail what difficulties your child has with each. This includes daily living activities your child is unable to do at all.
- List any medical problems your child has.
- List any psychiatric symptoms your child has.
- Describe the challenges your child faces in maintaining weight and managing food intake and food seeking.
- Discuss your child's future. Do you see your child being able to work full-time and independently earning enough money to live in their own apartment with no supervision? If not, share why this isn't possible for your child and why Social Security Supplemental Income and Medicaid are so important to your child's future.

We are attaching a sample journal written by one of our parents to give you an idea of how one parent described their child's situation. But, there is no right or

wrong way to prepare this journal. The key is to be as honest and specific as possible. If you would like us to review your journal before you submit it to Social Security, just let us know. We suggest you submit the journal attached to your Prader-Willi Syndrome Disability Evaluation form for Parents.

A Sample Parent's Journal

(Note: This parent's child was diagnosed later in life. Names and some circumstances have been changed to protect the identity of the writer and child.)

Name of Child: Betty Doe
Name of Parent: Carla Doe
Social Security Number: 000-00-0000

My daughter is 39 years old. She has experienced difficulties developmentally, socially, behaviorally, psychologically, and cognitively since she was born. Throughout her early life doctors posited several theories to explain her difficulties though a definitive diagnosis was not established until 2002 when a genetic test determined that she had Prader-Willi Syndrome. This is a rare genetic disorder. The major features include: cognitive impairment, behavioral disturbance, and a severe excessive eating disorder.

Betty is littered with impairments and disabilities; no single one (except the excessive eating) would automatically limit her ability to work within the usual settings. All the various problems taken together present an overwhelming picture of difficulty in ordinary circumstances. These difficulties have been present since birth and through Betty's schooling. Betty's elementary years were spent in a private school; the high degree of control and consistency in this environment provided a reasonable learning experience for her. Her first year of high school was very difficult and resulted in a placement in a residential school for two years. Betty returned to her public high school for her senior year with the support of a dedicated resource person. After high school, Betty applied for a Threshold Program for girls with developmental delays. Her application was denied because Betty's cognitive ability was too high and her social and interpersonal skills were too poor. Betty entered a practical nursing program but because of her behavior and manner was quickly asked to leave the program.

For one year, Betty worked part-time for a local grocer cleaning produce. When her hours were reduced, she refused to continue the job. Betty had difficulty coping with co-workers behavior towards her. She also gained significant weight

during this period and it became obvious to me that a grocery store was not an appropriate place for Betty to spend time without constant supervision.

I inquired about possible training for Betty with several agencies. The story was consistent. Her cognitive functions were too high for programs designed for the mentally retarded and her social and psychological abilities were considered too poor to be eligible for educational or vocational training for the learning disabled.

Betty now helps her cousin with housekeeping and childcare and volunteers at Sunday school at church.

The following is a list of many, but not all, of Betty's difficulties. The list is generated from my experience and many hours of discussion with Betty's teachers, psychologists, and doctors. I have included in Betty's application all of the documentation I have available.

Betty's cognitive impairments include:

- Severe auditory processing disability
- Language processing and expression problems
- A numeric memory of "1"
- Severe difficulties with short-term memory
- Sequential processing deficits (info intake, processing, and response production problems)
- Rigid thinking; little flexibility without lots of help
- A borderline IQ
- Balance and coordination are weak

Betty's behavioral problems include (but are not limited to):

- Inability to initiate or sustain day to day personal hygiene without help
- Limited sensibilities of "appropriate behavior"
- Little interpersonal ability beyond "meeting and greeting"
- Has no friends. She likes to be around people but rarely talks to others.
- Has no sense of time or the ability to manage a task inside of time expectations.

Betty's has problems with daily living skills including:

- Can bathe herself but cannot do the task in less than 2 hours.
- Can wash and dry clothes but takes 2-3 hours to sort 1 load of laundry, wash, dry, fold

- Can sort weekly recyclables but takes several hours; must do parts in rigid, absolute patterns
- Prepares simple meals (microwavable, scrambled eggs) but has little order, process from start through clean-up can take hours.
- Takes diabetic blood tests but cannot maintain schedule without constant prodding; takes 30 minutes to take test and document; cannot remember results; cannot establish causal relationship between blood levels and behavior; requires external management with minimal success.

Betty has psychological challenges including:

- Perseverates
- Stubborn
- Deceitful concerning food and diabetic patterns
- Unreliable reporting of eating and taking medication
- Cannot verbally express feelings
- Acts out
- Angry; cannot tolerate being an object of scorn, ridicule, accusation; this is a problem in school and work settings. Her only coping mechanism is to withdraw or freeze.

Betty has an excessive eating disorder. The insatiable appetite of someone with Prader-Willi Syndrome is due to a genetic defect where the hypothalamus never receives the message that the person is full. Because of this defect, a person with Prader-Willi Syndrome requires constant supervision or they will eat themselves to death. This is a lifelong and life threatening disability.

Betty has had Type II Diabetes for 10 years. Managing her eating requires constant vigilance and creativity. Her environment must be designed to keep food from her. If food is available, she cannot concentrate or focus on anything but the food. She simply cannot manage this by herself.

Betty's health is deteriorating slowly. Her blood pressure is borderline. Diabetes management is uneven. There are some ongoing questions about her heart function and possible gallstones.

Since I was laid off from my job almost three years ago, I have had the time to better manage and control Betty's day to day environment. I have not tried to replace my former position or salary because of Betty's needs in this area.

I believe I provide a sub-optimum solution to Betty's daily problems. Since the diagnosis of Prader-Willi Syndrome I have come to understand the needs of my

daughter more fully. She and I both agree that it would be better for her to live within an environment designed to support her needs. Approval for Social Security Supplemental Income would make this possible.