

Strategies and Tips for Dealing with Running/Elopement Behavior

Strategies:

- Locks to keep the person in the house.
- Motion detectors to alert others when doors are opened and the person might be leaving.
- Notify law enforcement in case the person gets into trouble or lost; use law enforcement statement.
- Have the person carry in their wallet the PWSA (USA) law enforcement card.
- Most running away occurs for two reasons: (1) Food seeking and (2) to be free from a life of restrictions/ The first can be addressed through behavior management and food security. The second can be addressed by trying to build in a sense of freedom and choice into the person's life.
- Contracting with a company/agency that can provide a GPS location of a wandering or lost person.

Tips from a Parent (name has been changed):

"Man oh man do I know how you feel! My Charlotte is 10 now and has been doing this for over 2 years now. I've tried and done all the things you've done. My end result? On the outside of her bedroom door, I've put a magnetic alarm, so as soon as the door opens it squelches, and as soon as it closes, it stops. In her bedroom, I've also placed a baby monitor so if she needs me, all she has to do is talk to me. That way, too, I can hear if her BiPap alarms. I keep the monitor in my room turned all the way up, so if she disconnects hers, I can hear the static and it alerts me that she's up to something. This has worked perfectly for us so far! Her Psychiatrist and Counselor both fully support this because it keeps her out of trouble without being cruel or endangering her safety by locking the door. She can still get out in an emergency (fire, earthquake, etc.) but she cannot get out, without me knowing, to food seek, run away or get into other things she's not supposed to. The alarms I bought were in the pharmacy department at WalMart (for medicine cabinets) and sometimes they're in the home improvement section. Hope this helps!

We HAD very similar situations at night and in the day as well. Two years back we decided to go to the annual PWCF general meeting and that was a LIFE-changing decision for the betterment of the entire family. My husband and I were constantly getting up to the sounds of the motion detector alarm at night, which is set above her bedroom door at an angle, and we almost shut the door so if she opens it to get out, it sounds off really loud. She would even try to glue herself to the wall and glide by it and combat crawl. Darn OT and PT can bite! Not to mention at that time we also had a six

month old and a two year old, so I was running on fumes of sleep. I was probably near a all time low. No sleep for years can make anyone crazy!

Tips from a Parent (cont'd):

Anyhow, at the conference we learned from the Pittsburgh EXPERTS that if she knew exactly what she would be eating at all meals and exact times, this would help with the seeking, stealing, nighttime foraging, etc., because there would be no anxiety around food and getting food. We set their guidance on behavior and food into action right away. When we would be driving in the car, she would bother us all the way home or anywhere and would throw anything she could get her hands on (shoes, toys and clothing) at us out of frustration. On our way from LA to Santa Clara, we promised her that we would stop at exactly 10 am for a snack, and exactly noon for lunch at XXXX and we did. Or you could say we will get you a hamburger, chicken salad, etc.; be specific. and 3 pm for snack and 6 o'clock for dinner. Their motto is NO DOUBT, NO HOPE. It was instant success for her and us. She started sleeping all night till 7 am and we have put a alarm clock and set it so she does not ask us any longer "Is it morning yet?" She now has a routine for all her activities and meals. I would highly encourage all parents to get the DVD and watch it in its entirety. Doctors Gourash and Forster have absolutely saved our lives. My daughter's weight has stayed steady and anxiety much lower. Another good point they made was LOW EXPRESSED EMOTION at all times, which seems impossible at 3 a.m.

Lack of proper sleep is draining for everyone, including the person with PWS. I personally feel the video and lecture in person was so beneficial that it should be mandatory for parenting a PWS child. I wish I had the information at the very beginning of life. It would have saved many tears, battles, tantrums, marriage problems, friendships, embarrassing situations in restaurants, public, and the list goes on.

By the way, we still use our alarm on her door that we got at Radio Shack. My daughter's first escape from the house was at age 5 at the wee hours of the morning. She managed miraculously to give the police, who happened to see her walking, our home address. We did not know that she had even left until the police started pounding on our door at 7 am. (she claimed she was walking her doll in the middle of winter with sandals and no jacket.) FYI, the cops did not press charges as they could tell she had something. We have now told her to tell police and teachers that she has PWS if she ever gets lost. I slept many nights in the hallway and my husband on the couch. Ever since the conference, we have not had a SINGLE episode of night waking or wandering."