



**Prader-Willi**

SYNDROME ASSOCIATION | USA  
SAVING AND TRANSFORMING LIVES

# Care Guide:

Preparing Babysitters  
and Respite Workers for  
Success with Your Loved  
One with PWS

# Welcome to Your Care Guide

*Created by Prader-Willi Syndrome Association | USA*

As a parent / caregiver of someone with Prader-Willi syndrome, you shoulder a tremendous amount of love, responsibility, and care each day. We know that entrusting your loved one to a babysitter or respite worker can be scary, but having the right tools in place can make all the difference.

This **Care Guide** was designed to support you in preparing babysitters and respite workers with the essential knowledge they need to care for your loved one with PWS. From documenting medical details and daily routines to outlining favorite activities and areas where assistance is required, this guide ensures that caregivers have a comprehensive understanding of your loved one's unique needs.

We also recognize the importance of taking time for yourself. Whether it's running errands, enjoying a date night, or simply recharging, you deserve peace of mind knowing that your loved one is in capable, well-informed hands. This guide helps provide that assurance while enabling you to step away when needed, knowing your child's care is well-managed.

Included in this toolkit are two **fillable forms** to document essential information, as well as **helpful resources** like "Supporting Someone with PWS" and the "PWS Medical Alerts Booklet."

Should any questions arise or additional support be needed, PWSA | USA is here for you with a 24-hour emergency crisis line at 941-312-0400.

**Your dedication and care are the foundation of your loved one's success, and we're honored to provide resources to help lighten the load.**

# Important Information for Babysitter or Respite Worker



*Our loved one has Prader-Willi Syndrome. Here are some important things to know.*

Address (for 911): \_\_\_\_\_

Main Emergency Contact(s): \_\_\_\_\_

\_\_\_\_\_

Pediatrician Name/Phone #: \_\_\_\_\_

Alternate Contacts: \_\_\_\_\_

\_\_\_\_\_

Secondary Diagnosis: \_\_\_\_\_

Medications/ Supplements: \_\_\_\_\_

\_\_\_\_\_

WiFi Password: \_\_\_\_\_

Poison Control #: \_\_\_\_\_

Other important Info: \_\_\_\_\_

\_\_\_\_\_

\_\_\_\_\_

**PWSA | USA Crisis Phone Line: 941-312-0400**

Website to find additional resources: [www.pwsausa.org](http://www.pwsausa.org)

# About Our Loved One



## Details of Diagnoses

- Prader-Willi Syndrome:
  - See attached brochures
  - Food security is very important! No food is to be given other than what has been previously discussed or set aside. They must be fully supervised while eating or while the food is accessible.
- Secondary Diagnosis (*if there is one*): \_\_\_\_\_
  - Important details: \_\_\_\_\_  
\_\_\_\_\_  
\_\_\_\_\_

## Interests (e.g., movies, books, characters, games, activities)

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## Assistance Needed (e.g., use timer or countdown when transitioning between activities, offer only 2 options when choosing a book or game, must be supervised when outside)

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## Things We're Working On (e.g., saying please and thank you, washing hands after using the bathroom)

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## Stimming Behaviors / Signs of Anxiousness - How to Manage (e.g., skin picking - distract, find something to occupy hands; perseveration on topic - give specified amount of time to discuss and move on)

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# Helpful Resources



## Brochures

- Supporting Someone with PWS..... [DOWNLOAD](#)
- What Educators Should Know..... [DOWNLOAD](#)
- PWS Medical Overview..... [DOWNLOAD](#)
- Helping All Families and Professionals.... [DOWNLOAD](#)
- Someone You Know Has PWS..... [DOWNLOAD](#)
- Questions and Answers About PWS..... [DOWNLOAD](#)

## Booklets

- PWS Medical Alerts Booklet..... [DOWNLOAD](#)

## PWS Fact Sheets

- Infants..... [DOWNLOAD](#)
- Toddlers..... [DOWNLOAD](#)
- School Age and Young Adults..... [DOWNLOAD](#)
- Adults..... [DOWNLOAD](#)

## Website

- PWSA | USA's Website..... [ENTER HERE](#)
- Medical Issues A-Z..... [ENTER HERE](#)