Find Your Voice:
Advocating for PWS Health Care Webinar Series

Health Education and Advocacy for Parents and Caregivers

Session 3
OBJECTIVES

- Grow confidence in health advocacy
- Identify ways to find information
- How to come prepared
- Grow confidence in more common urgent health issues
Parents and Caregivers are the primary advocates throughout the life span.

The first step in confidently advocating is becoming informed and educated.
There are numerous ways to stay informed
TOPICS

Concerns for the Hospitalized Person with PWS

- General Information for Patients in the Emergency Department
- Anesthesia and Postoperative Monitoring
- Medication Sensitivity
- Food Security in the Health Care Setting
GENERAL INFORMATION FOR PATIENTS IN THE ED
COMMON REASONS ED IS USED

- Choking
- GI Issues
- Bone / Joint Injury
- Psychiatric Emergency
**GOALS, TRUTHS, CHALLENGE**

- Goal of an Emergency Department
- Truths: People with PWS are a diagnostic challenge
- Biggest Challenge: Making the health care provider believe what you are saying
Things to Keep in Mind

- ED staff are NOT familiar with PWS
- You’re the teacher
- Be Patient
- Take GI issues SERIOUSLY
- Get an x-ray
- Medical Alerts Booklet
ADVOCACY TIPS

PRADER-WILLI SYNDROME
MEDICAL ALERTS

Medical Alerts Booklet
GI Algorithm
Medication List
Physician Contact Info
941.312.0400
Up-to-Date

941.312.0400 | www.pwsusa.org
MORE ADVOCACY TIPS

Collaborate  Calm and Respectfully Aggressive  Negotiate
People with PWS who need any kind of anesthesia, surgery, or any procedure that requires anesthesia must have close monitoring and need special considerations.
TYPES OF ANESTHESIA

- General Anesthesia
- Conscious Sedation
SURGICAL AND ANESTHESIA RISK FACTORS

- **Obesity**
  - All people with PWS who are obese are at increased risk of experiencing complications with either type of anesthesia
- **High Pain Threshold**
- **Temperature Instability**
- **Thick Saliva / Narrow Throat**
- **Food Seeking Behaviors**
- **Low Muscle Tone / Respiratory Concerns**
- **Skin Picking**
- **Difficult Starting IV**
- **Behavior Concerns**
- **Slow Recover**
- **Slow GI Movement**
ADVCACY TIPS

- Address Dental Concerns Prior to Surgery
- Share Anesthesia Handout
- Overnight Monitoring in Hospital
MORE ADVOCACY TIPS

- First Case of Day
- Extra Supervision when Fasting
- Respiratory Therapy
- Movement / Walk
- Monitor Tubes
- Most Skilled Person doing IV
- Caregiver Supervision
- Communicate ALL Medications
- Share GI Chart
MEDICATION SENSITIVITY

Things to Know:

• People with PWS are extra sensitive to many medications.
• Anesthesia, pain medications and medications used to treat mood or behavior problems are some of the most common medications that can cause an exaggerated response.
• Use a slow, conservative approach “start low and go slow”.
• Medications that impact the functioning or motility of the stomach and GI tract can also cause a more severe response.
ADVOCACY TIPS

- Share the Medical Alerts Booklet
- Use extreme caution in using medications to treat diarrhea
- Share a list of all medications, including vitamins and supplements
FOOD SECURITY IN THE HEALTH CARE SETTING

Managing food security is VERY challenging

Need for Oversight when not mealtime

Binge Episodes

Extraordinary Weight Gain

Water Intoxication

Headaches / Fatigue

Nausea / Vomit

Loss of Consciousness

Managing food security is VERY challenging

Need for Oversight when not mealtime

Binge Episodes

Extraordinary Weight Gain

Water Intoxication

Headaches / Fatigue

Nausea / Vomit

Loss of Consciousness
ADVOCACY TIPS

- Supervision and advocacy in the hospital is very important
- Request a nutrition / dietary consult
- Educate staff of dietary and food seeking needs
- If possible, request a private room to limit the access to roommate’s food
- Constant monitoring of food cards with delivery and removal of food
- Block ability to order food by phone
- Limit access to kitchen on the nursing unit
- Check waiting room areas
- If possible, ask that ONE staff be assigned responsibility for providing all food and beverages each shift
- Check weight daily
SUMMARY

• It is very stressful when a person with PWS is hospitalized
• We hope that this presentation has provided you with the information, tips, and resources to help you when your loved one is hospitalized
• YOU are a very important person in helping the person with PWS receive appropriate, prompt evaluation and treatment for their health concern
Open Discussion

Q & A
RESOURCES

PWSA | USA Medical Alert booklet

www.pwsausa.org

Info@pwsausa.org

941-487-6755