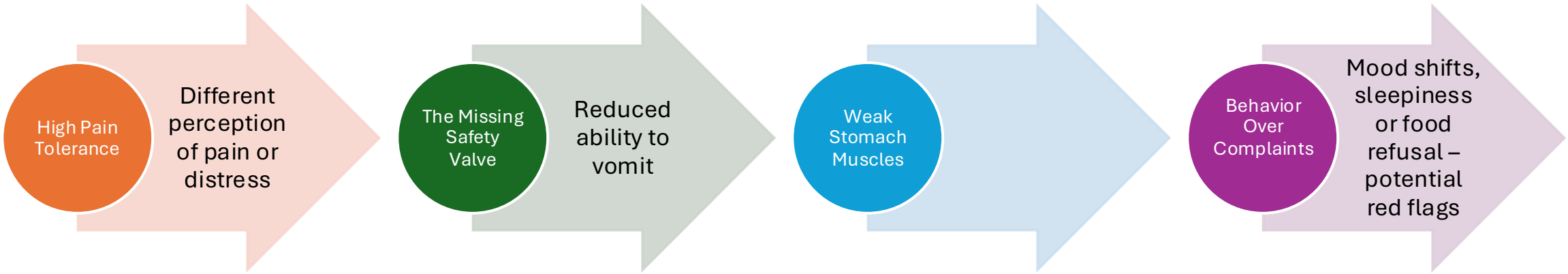
Guarding the Gut: GI Health, Food Security and Medical Emergencies : A Caregiver’s Guide to Environmental Protection and Crisis

Ann Scheimann MD MBA

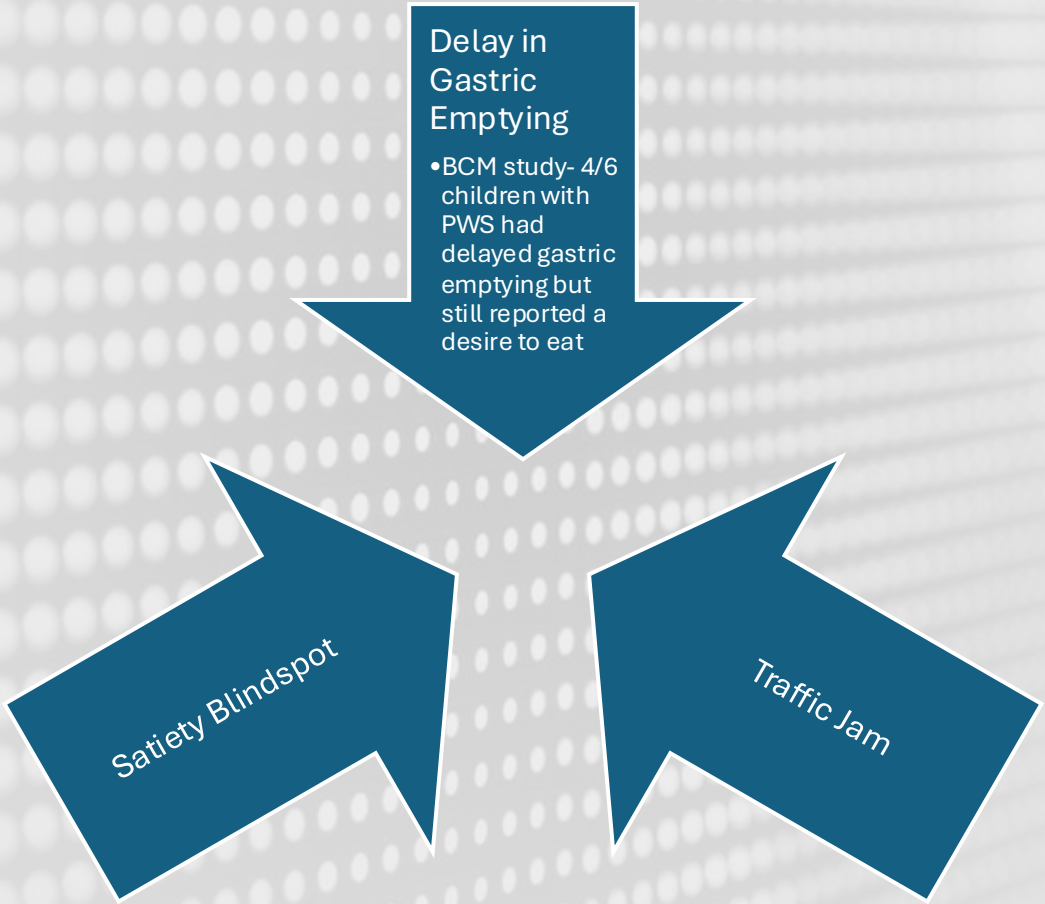
Professor of Pediatrics

Johns Hopkins School of Medicine

Why PWS Makes GI Troubles- Silent and Hard to See



Gastric Emptying: Why the Stomach Stays Full



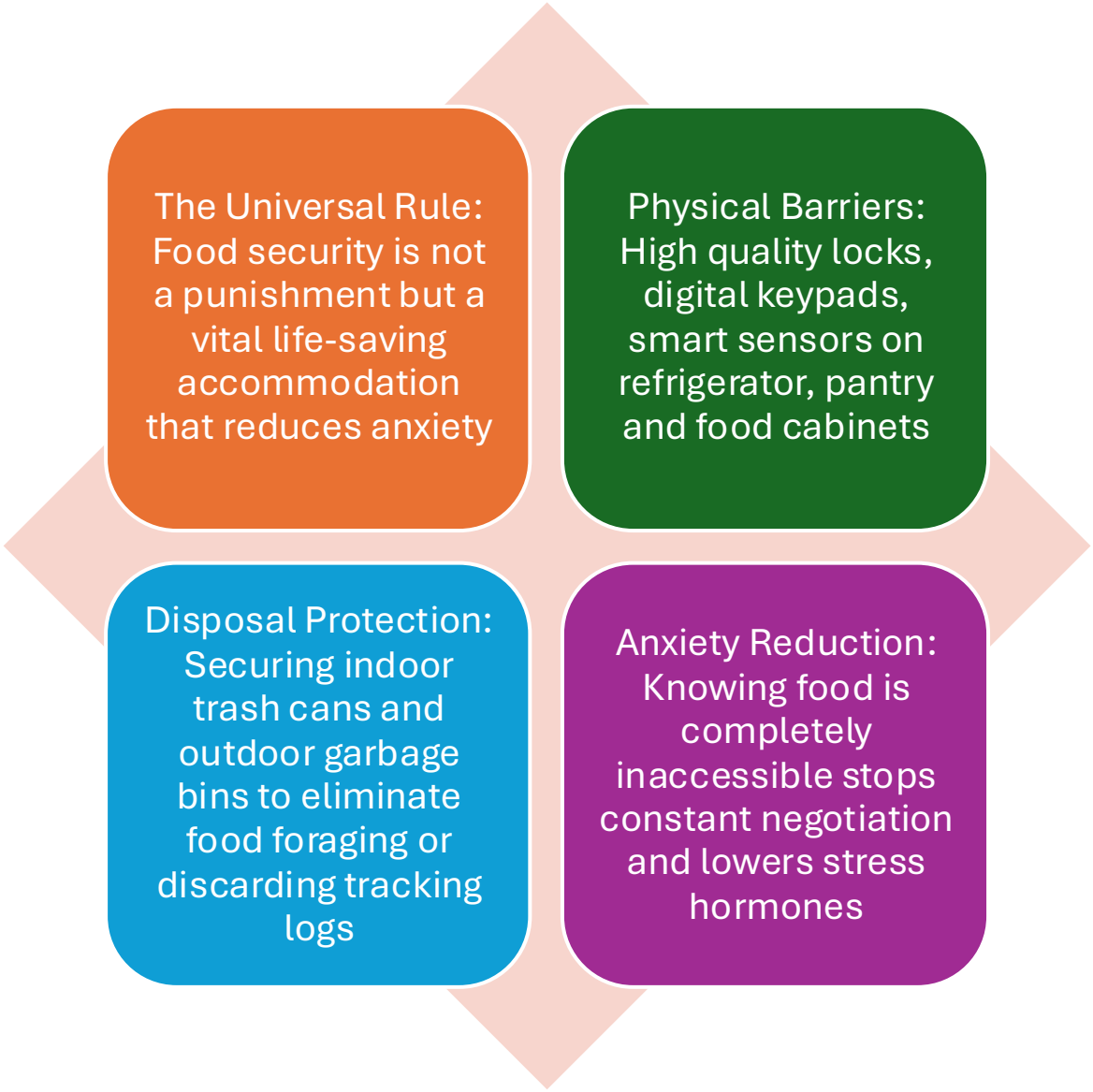
Severe Stomach Stretching (Gastric Dilation)

The Threat: Unsupervised access to large amount of food (binge), their slow stomach cannot pump it out

Thinning and Tearing: Stomach stretches until the walls become thin cutting off the blood supply and causing tissue necrosis

The Ultimate Red Flag: Except in rare circumstances, vomiting in PWS is a medical emergency- not a “simple stomach bug”

The Principles of Environmental Food Security



Operational Food Security: Execution and Routines



Extending Food Security Outside the Home



School Action Plan: Formalize food security protocols within IEP or 504 plans (locked teacher lounge, lunch line monitoring



Vehicle safety: Lock grocery bags in the trunk. Do not leave snacks, mints, fast food wraps in the main cabin in the care



Money Restrictions: Eliminate unmonitored cash, debit cards, smartphone pay apps which could be used at vending machines, doordash or convenience stores



Shadow protocol: Have designated, trained adult responsible for line-of sight supervision during transitions between activities

Navigating Parties, Holidays, Family Gatherings

Designated Guardian: One adult is sole food supervisor for the duration of the event

Pre-Briefing the Host: Educate family members and hosts before arriving and request that buffet or candy bowls be placed out of reach

Place Control Strategy: Serve pre-measured portion directly, clear their plate immediately and step away from the dining area

Airtight Tracking: if a slip up or possible binge occurs, document immediately and begin 48 hour monitoring

Advocating in the ER: The PWS GI Algorithm

The Physician Blindspot: ER doctors are trained to look for a rigid, painful abdomen which a PWS patient may not show

The Script to Memorize: Tell the ER physician " My child has PWS. Their pain response is masked- their stomach exam can look normal, just like a patient on high dose steroids or narcotics

The First Commands: Demand that they make the patient NPO (no food or water), insert a tube through the nose to relieve pressure in the stomach and order a stat X-ray or CT scan.

Decoding the Algorithm Management Plans

Hunt for Air- Xray and CT scan check for dilation/swelling of the stomach and for "free air" which can suggest a tear or rupture

Fork in the road

If a tear is present- need emergency surgery	If there is stretching but not tear- admission with careful surgical monitoring, tube drainage, IV fluids and serial monitoring with exams and films.

The Hidden Burden of Chronic Constipation



Daily Bowel Management and Cleanout Warnings

Daily protocol: keep stool moving using a “musher” (miralax) paired with a doctor-guided pusher (senna) to help weaker muscles contract

Cleanout hazard- need to modify cleanout plans due to issues with liquid tolerance and gastric volume

Bottom-up rule: Per the PWS algorithm- doctors should check for a blockage- (rectal exam or gentle enema) before giving large amounts of cleanout liquids orally.

New Tools, GLP-1 Medications

- The Clinical Trend: Medications like Ozempic, Wegovy or Mounjaro are increasingly used for PWS adults with diabetes
- The Weight Reality: Studies show they are excellent at controlling blood glucose in PWS but rarely alter weight or BMI in this population
- The Gastrointestinal Warning: These injections work by slowing down the stomach. In PWS this can compound gastric atony and dramatically increase the risk for severe stomach stretching



Your Action Plan: Main Takeaways

- Trust Your Instincts: Behavioral changes or sudden fatigue are your earliest warnings- don’t wait for complaints of pain
- Vomiting- Head to the ER.
- Lock It Down: Implement structural, operational and mobile food security plans to keep the environment safe
- Be a Fierce Advocate- Bring the PWSA GI Algorithm chart with you to the ER, hand it to the provider and request evaluation