



IPWSO

**International
Prader-Willi Syndrome
Organisation**

Preventing Challenging Family Life

Lynn Garrick

OBJECTIVES





MY STORY

CHALLENGES FAMILIES FACE

- Physical and emotional exhaustion
- Financial
- Family members not understanding
- Isolation
- Behavioral challenges
- Sibling conflict
- Marital difficulties



FINDING
RESOURCES

IPWSO

PWSA USA

FPWR

Other regional PWS
organizations
Facebook groups

Community disability
organizations and groups

PREVENTING CHALLENGES



Educate

Security

Consistency

Expectations/boundaries

Time for yourself and others in the family

Communication

EDUCATE

01

Start with
your
immediate
family

02

Have routine
family
meetings

03

Create a
game plan
that
everyone

SECURITY



Food security plan



Home security plan



Community security plan

CONSISTENCY

Consistency is the key

Everyone should be on the same page

Do NOT give into behaviors. This has a snowball effect

The PWS individual thrives when they know what to expect

CONSISTENCY IN BEHAVIORAL APPROACH

Needs its own
talk

continue or
create a
power
struggle (you

Role model

word "no"
use limited
guided

Stay calm

Don't make
threats

doesn't mean
you agree
with the

Redirection

EXPECTATIONS AND BOUNDARIES

01

Have clear expectations for the PWS

02

Model those expectations

03

Let the individual know what they are

04

Use social stories

EXPECTATIONS
AND
BOUNDARIES
CONT.

Define boundaries

Model

Social stories

Praise when you see use
of boundaries
Ask questions

COMMUNICATION

1

With your partner

2

With your family/friends

3

With medical team

4

With school

5

With people in your community

TIME FOR YOURSELF AND OTHERS

For many this seems impossible

-Come up with some type of plan

nap/sleep time

Utilize other trusted family members so you can schedule time for yourself and other

- Utilize community resources



FIND JOY

- Celebrate moments no matter how small
- Keep track of small wins
- Practice radical acceptance
- Be gentle with yourself and others

MY "I WISH I WOULD HAVES"

- Not isolated myself
- Asked for help
- Stuck to a meal plan
- Not given in to behaviors because I was too tired both emotionally and physically
- Developed a routine
- Taken time for my mental health
- Talked with my other children more
- Not entered power struggles
- The list goes on...

REALITY CHECK

No family is without challenges

PWS can be a unique opportunity to unite not divide the family

Arm yourself with all the education you can

Build your family toolbox



??QUESTIONS??

Thank you!

Lynn Garrick

lynnmgarrick@comcast.net

LINKS

- <https://ipwso.org>
- <https://www.pwsausa.org>
- <https://www.fpwr.org>

