PARENTING: SUPPORTING THE WHOLE FAMILY

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PARENTING IS ALL ABOUT HOW YOU HANDLE PLAN B.

EVER HAVE A JOB WHERE YOU HAD NO EXPERIENCE, NO TRAINING, YOU WEREN'T ALLOWED TO QUIT, AND PEOPLE'S LIVES WERE AT STAKE?

THAT'S PARENTING.
INDIVIDUALS WITH PWS
AND THEIR FAMILIES

**Pros for Families:** Reduced societal stigma, increased acceptance, accommodations, support, access, fewer restrictions

- reduced stress on families, confidence in parents, alleviates anxiety

**Cons for Families:** Stress on parents overlooked, sibling stress and adjustment problems an afterthought?

- neglected needs of family members?

SUPPORTING THE ENTIRE FAMILY OF SPECIAL NEEDS INDIVIDUALS (ALL AGES)

- Awareness: how family members (other, appreciation, pay attention, validate, praise, reward)
- Reach Out to Others for support (family members, friends, PWSA, professionals)
- Understand/that we continually need to learn new ways to cope
- Create or Build a Support System or "team" for every family member
- Radical Acceptance: of a different experience of family and togetherness

HIGH NEEDS CHILD =
HIGHER PARENTING NEEDS?
IMBALANCE?
STRESSORS FOR FAMILY MEMBERS

- Presence of others (During family time — aides, therapists, in any, extended family)
- Quality of family time and attention to all family members
- Medical and healthcare
- Access to people, places, services
- FOOD: Where, when, what, how...
- Responsibilities (for parents, sibs, extended family)
- Leadership and control by family members
- SPECIAL ACTIVITIES, travel, vacations, outings, events
- TIME!

Parents and Siblings of PWS Individuals:
RISKS

- Trouble sharing feelings with other family members
- Resentment and negativity
- Isolation and envy
- Hopelessness
- Anger, rebellious, opposition, defiance, complaints, rejection
- Friendships, socialization, and peer acceptance
- Neglect, unappreciation
- Increased emotional suffering and burnout
- Underappreciation, feeling taken for granted, minimizing
- Unable to cope, family conflict and dysfunction

Sibling Issues

- Isolation, withdrawal (from family or peers)
- Hidden problems (fear of overwhelming parent)
- Feeling like problems not valid, "toughen up"
- Parentification of older siblings (loss of childhood)
- Sibling conflict, rejection, loneliness
- Behavioral problems (across all ages?)
- Missed, ignored or minimized achievements
- Feeling "in the dark," lack of understanding — FEAR, WORRY
- Food stress in the home, outings, holidays
- Peer stress (embarrassment, time sacrifices, need to protect)
Sibling (and Family) Challenges vs. Benefits

<table>
<thead>
<tr>
<th>Challenge</th>
<th>Benefit</th>
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<tbody>
<tr>
<td>Insensitivity</td>
<td>Dependable, loyal and sensitive adults</td>
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<tr>
<td>Rivalry, jealousy</td>
<td>Patience, self-control, delayed gratification</td>
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<tr>
<td>Negative emotions</td>
<td>Kindness, understanding, empathy</td>
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<tr>
<td>Imbalance in attention and time</td>
<td>Independence, responsibility</td>
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<tr>
<td>Worry and Fear</td>
<td>Empathy and compassion for others</td>
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Other benefits: Gratitude, understanding individual differences, generous

KEYS TO PARENTING SIBLINGS

- Talk open and honestly (how honest? What is developmentally appropriate? Do we shield younger sibling? What information do we share?)
- Help build acceptance (talk about strengths and weaknesses, do not force)
- Address fears as they come up (do not create unnecessary worry)
- Encourage question-asking
-Special time: 1-on-1 on regular basis and schedule “dates” (both parents, put on calendar)
- Parents should discuss and address imbalances in parenting
- Be alert to emerging behavioral problems
- Red flags for emotional problems (quiet, alone, sad, withdrawn, angry, fearful)

KEYS TO PARENTING SIBLINGS CONT’D...

- Avoid the guilt trap (over-indulgences, spoiling, giving in, no rules)
- Don’t assume capabilities of siblings (more or less)
- Praise achievements no matter how big or small
- Note positive qualities (tolerance, sensitivity, help/assist, sacrifice, understanding)
- Try to be empathetic
- Avoid pressuring siblings to speak, feel, or behave a certain way
- 1-on-1 discussions versus family discussions
- Food... find a balance between over-restriction and indulgence, hiding food
MENTAL HEALTH OF SIBLINGS

RED FLAGS
Greater risk for anxiety and depression due to chronic adjustment stress
Younger children: may become demanding, rigid, defiant, withdrawn, stubborn, angry, tantrums, aggressive toward sibling, learned helplessness
Pre-teens and teens: withdrawn, peer problems, academic problems, fearful or anxious, sad, depressed, hiding feelings, hopeless, isolated, rejecting

FINDING OUT A NEW BROTHER OR SISTER IS NOT WHAT EXPECTED = DENIAL
Life lesson of unfairness (sadness, why us? why me?)
Anger over parent attention, extra efforts, loss of certain family experiences
Frustration and resentment with feelings of helplessness
Emotions related to expectations and obligations to help
Reaching out, finding other siblings ("holding it in makes it worse")
Appreciation for sibling, seeing the special qualities, "being amazed"

REFLECTIONS ON GROWING UP WITH SPECIAL NEEDS SIBLING

Implications for Parenting Individuals with PWS

CHALLENGES FOR PWS INDIVIDUALS:
- Food issues
- Autism traits: rigid/unflexible, OCD, anomalies
- Language, processing, speech, communication
- Lower IQ/Developmental delays
- Excellent memory, need for reassurance, repeat
- Preference for solitary time, isolation
- Difficulties with theory of mind, perspective
- Physical limitations

PARENTING TIPS/TOOLS:
- Environmental change, balance family needs
- Practice flexibility, keep routines/schedule
- Limit verbiage (simple, key point, visual lists)
- Adjust/rely expectations to succeed
- Schedules and routines are our friends
- Modify notions of family togetherness
- Behavioral strategies versus develop insight
- Balance family needs (more 1-1 time)
THE MAGIC KEYS TO PARENTING
UNDERSTAND REASONS FOR MISBEHAVIOR: Attention, Power, Revenge, Display of Inadequacy, family dysfunction?
USE LOGICAL CONSEQUENCES
USE REWARDS
REDUCE FREEDOM
STRUCTURE TIME
PLAN FOR TRANSITIONS
USE "PREPARING/ANTICIPATE"
KEEP ROUTINES AND SCHEDULES
SPEAK AT CHILD'S LEVEL, KEEP IT BRIEF
USE COMMANDS/NOT QUESTIONS
LIMIT CHOICES IF YOU ARE GIVING THEM
HELP BUILD ACCOUNTABILITY: "you can choose..."

BUILDING RESILIENCY IN FAMILIES

SIBLING RELATIONSHIPS
WHAT ARE THE INFLUENCING FACTORS FOR YOUR FAMILY?
Parenting A Child with PWS and Their Siblings: A Word about Grief

• Parents of special needs children should address their initial grief associated with diagnosis. Some individuals may not realize they are experiencing grief. Avoidance leads to displaced feelings, higher parenting stress, withdrawal and isolation.

• SIBLINGS also experience symptoms of grief.

• GRIEVES STAGES: Denial, Anger, Bargaining, Depression, Acceptance...Where are you?

• Factors impacting our grief: new diagnosis, limited understanding, how and when diagnosis shared, # of children, sibling position of PWS child, experience level of parent, family stability, single parents and divorced parents, parenting capacity prior to diagnosis

• GRIEF IMPACTS OUR RELATIONSHIP WITH PARTNERS.

• Acceptance that we will face ongoing loss and grief as our children mature (inability to achieve or reach certain goals, quality of life for child, siblings, family as a whole, future launching, financial planning issues)

WHAT PARENTS NEED MOST

• SELF CARE
• SELF-HELP
• REACH OUT TO TRUSTED PERSON (Parent, mentor, clergy, friend, medical professional, therapist, family, PWSA)
• WHEN DO WE NEED PROFESSIONAL HELP? (impacting daily functions)

• RED FLAGS: isolation, withdrawal, sad mood or crying, changes in appetite and/or sleep, pain or illness, chronic worry, abusing mood-altering substances

• INDIVIDUAL AND/OR COUPLES COUNSELING

Parents and Compassion Fatigue

Chronic stress can lead parents to experience emotional numbing, denial, avoidance, angry behaviors or flight (running away).

Empathy without compassion leads to BURN OUT

Self-compassion is needed in order to pool our own resources

Put on your own oxygen mask... create special time for YOU

Need for daily mantras and coping statements

Importance of compartmentalizing to avoid stress leaking into other areas of our lives.
SELF COMPASSION: Parent well-being?

- Self-kindness versus self-judgment (treat with care, not harsh, soothe, not blameful)
- Common humanity versus isolation (larger human experience, life is imperfect)
- Mindfulness versus over-identification (“I’m” with painful feelings, avoid extremes)
- Negativity bias (we hear more negative than positives)
- Need to savor the positives and hold gratitude
- Children observe self-compassion in parents or lack thereof (then model, self-critical?)

BREAK OUT GROUPS

QUESTIONS?

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