# PRADER-WILLI SYNDROME ASSOCIATION Still hungry for a cure.

# Laughter After Tears: Building a Strong Family Creating a strong, supportive and healthy marriage and family

Janalee Heinemann, MSW and Lisa Graziano, M.A., MFT

Looking at coping mechanisms to create a strong, supportive and healthy marriage and family.

#### What are the components of a healthy marriage?

#### Characteristics of a "healthy" marriage.

The good news and the bad news is that there is not just one way to have a strong, healthy marriage. What works well for one couple may work horribly for another.

All couples disagree, fight, feel exasperated, angry, stressed, and hurt at various times throughout their marriage. Couples in healthy marriages disagree and fight about the same things couples in unhappy marriages typically fight about – money, sex, in-laws, chores, childrearing – but they fight in such a way that somehow communicates an overall caring about the other, an overall regard for the other's ideas, concerns, opinions, wants and needs. They know that keeping the relationship healthy is more important than the thing they are fighting about, and that if their marriage is strong they *will* find a way to resolve the issue. They also know that not every problem *can* be solved.

A healthy marriage is created when the couple creates a style of relating with each other that works best for *them* based upon their individual personalities, beliefs, and life experiences. There are, however, certain characteristics that are shared by couples who have a healthy marriage.

#### 1. **Deep Friendship**

Couples who have a mutual respect for each other, who truly enjoy each other's company, and who stay in tune with their spouse's day-to-day world are the happiest. Happy couples know each other's likes, dislikes, personality quirks, hopes, dreams, fears, stresses, and knee-jerk reactions to stressors. "They have an abiding regard for each other and express this fondness not just in the big ways but in the little ways day in and day out." (Gottman 1999) Couples who have created a healthy marriage have a genuine caring and respect for their partner.

In unhealthy marriages couples criticize, disparage, undermine, become cynical, sarcastic, defensive, devalue the friendship, ignore each other, live separate lives, and are often lonely and depressed. In a healthy marriage each spouse generally treats the other well.

#### 2. Sense of Purpose

In strong marriages couples share a sense of purpose for their marriage. For some, an overriding purpose of marriage may be to connect with another human being in order to create a safe haven within which to pursue individual hopes and dreams. For others the purpose of marriage may be to have children and raise them to become responsible adults who then marry and have children of their own thus perpetuating society. For a spouse who holds the latter belief, having a child with PWS may present a particular challenge and present an added loss.

Our own personal beliefs about marriage, whether conscious or not, are shaped and influenced by our experiences within our family of origin and will influence what we think our married life should be like (fantasy), what we do to achieve that fantasized life, and ultimately we how behave toward and interact with our spouse.

In a healthy marriage, the couple is able to value and support their partner's individual hopes and dreams and work together to create shared family goals.

#### 3. Stay Connected

Couples in healthy marriages stay emotionally connected with each other. They turn *toward* each other, whether it's during times of excitement or times of stress. They don't dread sharing their fears, stress, or disappointments. They look forward to sharing good feelings or good news with their partner. They reminisce about their shared experiences, good and bad.

#### 4. Shared Authority

Couples in a healthy marriage seek out the advice, opinions, and experience of their spouse. They don't make major decisions that might affect the family without their spouse's input or before first discussing it. Even when they don't agree with their spouse's opinion or concerns they don't belittle or disparage them. They know how important it is to the marriage to learn more about *why* their spouse believes as they do, and they bear in mind their spouse's concerns while discussing the best course of action. Couples in a healthy marriage work together cooperatively for the good of the entire family.

## The impact on marriage when a child has Prader-Willi syndrome

Unfortunately, the odds are against any marriage lasting "until death to us part." Half of all divorces occur within the first seven years, and the divorce rate jumps to 67% over a forty-year period. The divorce rate for second marriages is as much as 10% *higher* than first-timers! (Gottman 1999)

All change, whether welcome or unwelcome, is stressful. Having a baby certainly presents a change to the couples' family structure and places a tremendous amount of stress on any marriage. In a study by Gottman (1999) one of the major causes of marital dissatisfaction and divorce was the birth of the first baby!

Receiving the diagnosis of Prader-Willi syndrome creates massive stress and usually triggers feelings of loss, depression, and grief. As the child grows, new stressors replace or compound previous ones.

Each of us reacts to stress depending upon our individual character makeup, temperament, family-of-origin and life experiences, and learned coping strategies. Our reactions to stressors reflect the way we choose to protect ourselves from becoming overwhelmed, which for couples who have a child with Prader-

Willi syndrome represent some of the *highest* levels of stress. Like other couples who have a child with a disability, the stress created by PWS will impact the couple; they will respond by beginning or continuing to work together as a united team to respond to the new challenges they face, or they will turn away from each other and begin the process of disengaging from their marriage. *This is a critical dynamic in the marriage of a couple who has a child with PWS and will impact the entire family dynamic throughout the years ahead.* 

Having a child with PWS often provokes a sense of loss, often multiple losses. Loss can be composed of many intense emotions including sadness, grief, despair, anger, guilt, fear, worry, isolation, loneliness, shock, jealously, shame, and guilt. Some reactions to loss are humanly common: denial (this isn't happening to me!), anger (why is this happening to me?), bargaining (I promise I'll be a better person if...), depression (I don't care anymore), acceptance (I'm ready for whatever comes). These feelings are not necessarily felt in that order and there should be no presumption that they progress through "stages" or that once they are worked through they never need to be experienced again.

Feelings of loss can be devastating. We experience a loss of the excitement and joy we imagined we'd feel after the birth of our baby; a loss of the ease and normalcy we see others around us appearing to enjoy; a loss of friends or relatives or work peers we leave behind when they can not accommodate to our new needs; the loss of becoming a grandparent; the loss of the fantasy we had once created for our child's, our self and our family's future.

Having a child with Prader-Willi syndrome means we will probably experience *chronic* loss or *chronic* grief. Grief doesn't leave us completely, but the intensity of the feelings does lessen over time. This lessening of the intensity of feelings may be considered a kind of "acceptance" and can be defined as a coming to terms with the loss. Each new developmental phase our child progresses through may kick up feelings of loss and grief. While we may come to some kind of "acceptance" today, *tomorrow's* circumstances may trigger a re-experiencing of denial or anger or depression or all three simultaneously. Additionally, any new losses tend to stir up previous losses, which can intensify the feelings associated with the new loss.

Worden, Leick and Davidsen-Nielson (1991) describe four basic tasks that individuals need to achieve in order to integrate their experience of loss into their life and move toward investing in a new life without the lost loved one. These can be applied to the parents of a child with Prader-Willi syndrome, though they will occur again and again throughout the marriage and the child's lifetime: 1) Recognize the loss;

2) Release the emotions of grief; 3) Develop new skills (take on new role, make new contacts, friends, support network. Incorporate the experience of the loss into one's identity. The opportunity for personal growth and development is seen in this part of grief work; and 4) Reinvest emotional energy in the present.

Of particular challenge to parents with a child who has PWS is

the fact that spouses may very well be at a different emotional places; while one parent may be closer to the realm of "acceptance" and ready to make an action plan, their spouse may be fully involved in denial, or anger or depression. While one spouse may be ready to connect with a PWS support group or other parents, their spouse may not be ready to deal with the syndrome. It is important to remind ourselves that we must allow our own process to proceed at its own pace and we must tolerate and support our partner's process as it proceeds at its own pace.

Understanding that the grief we feel is chronic may provide us greater motivation to seek out ongoing support systems and help us develop patience and a deeper understanding of ourselves and our spouse who is also experiencing chronic grief.

Author Leo Buscaglia once talked about a contest he was asked to judge. The purpose of the contest was to find the most caring child. The winner was a four year old child whose next door neighbor was an elderly gentleman who had recently lost his wife. Upon seeing the man cry, the little boy went into the old gentleman's yard, climbed onto his lap, and just sat there. When his mother asked what he had said to the neighbor, the little boy said, "Nothing, I just helped him cry." Sometimes we all need a little help from our spouse just to cry.

While most marriages fail within the first seven years, most children are born within the first seven years which means that more than half of kids will grow up in a divorced family. All children are negatively impacted when parents divorce – even the most civil divorce creates stress – but children with PWS especially need an even *greater* degree of stability, routine and low stress environment. While no couple ever wants their marriage to end in divorce, we often place the focus on our marriage at the very bottom of the priority totem pole, underneath all of the things we *have* to do for our child or children. And all too often we view our spouse as just another *cause* of our stress.

But it doesn't have to be this way. If not for the sake of our marriage, then for the sake of our child it behooves us to work together with our spouse to create a strong marriage and a supportive family atmosphere. And in the end, once we practice the skills and techniques and place importance and emphasis and value on our spouse and our marriage we will reap the benefits of a mutually satisfying, loving, healthy marriage and strong family.

#### **Common Stressors on the New Family**

Each of us reacts to stress differently depending upon our own individual character makeup, temperament, and learned coping strategies. The couple shares the experience of loss, but each individual may react quite differently. Recognizing and bearing in mind the typical stressors on your spouse may help you have a deeper understanding of and more compassion for them, thereby strengthening the intimacy between the couple. It is our responsibility to take action when we there is a stressor we can help reduce for our spouse.

No matter what the circumstances the birth of a baby is stressful on a marriage. The amount of stress is compounded by the degree of trauma associated with the baby's delivery and the severity of the baby's symptoms. Additional stress is experienced when parents receive the diagnosis.

We all empathize with new mothers' lack of sleep, but it is important not to forget about the new father's lack of sleep. Lack of restful sleep keeps both parents from reacting as calmly as we might normally.

Men typically react to stressful events by trying to do something about them. In order to be in a ready state to "do," whether it be making phone calls, signing papers, speaking with physicians, comforting his wife, men frequently believe they must not allow themselves to become emotional. For many fathers, "doing" is working hard not to become emotional. He may fear that turning to his wife and sharing his feelings will cause him to feel too vulnerable and push him over the emotional edge. As a result, he may choose more emotional distance from his feelings and from his wife in order to sustain his ready-to-do-state (to which she may feel additionally stressed by her perception of being neglected, shut out, emotionally abandoned).

Not being able to do anything to correct the "problem" can create even more stress for a father. He may try various strategies to "fix" things: reassure his wife that everything will be okay (to which she may feel additionally stressed by her perception that he is in denial, doesn't understand the situation at all, and therefore she will have to do everything by herself); or he may choose to focus on securing the family's financial and health insurance status by working more hours or more intensely (to which his wife may feel abandoned, overwhelmed, and resentful); or because he may feel afraid to physically handle the baby, he may look for something else useful to do such as work more hours, focus on house or car repairs, research the syndrome, etc. (to which his wife may feel additionally stressed by her perception that he is not physically present to help her).

Women typically react to stressful event by wanting to talk it out... literally. Women often feel a physical relief while sharing stressful feelings. New mothers often feel intense feelings of vulnerability and dependency upon her husband and will look for reassurances from him that he will "be there" for her. She may want to talk about her experiences in order to relieve her stress (to which her husband may feel additional stress at the perception he needs to "do" something to help her). Women often expect their husbands to be as solid as a rock and when they are not as solid as expected, especially during times of stress, they may feel very scared or angry and protect themselves by turning or pulling away.

Common situations in new families often become intensified when the child has PWS. The demands upon the couple to make constant adjustments and negotiations are intensified; nighttime feeds are not the typical simple nighttime feeds, etc. Post-partum depression symptoms may need even greater and more intense intervention. Maintaining employment and health insurance benefits become paramount and may place even

greater stress upon the working spouse.

New fathers typically don't feel overly confident holding and caring for a young infant. They may feel afraid they'll somehow injure the child, either by holding the baby in such a way it will be smothered or receive injury to the neck, or by feeding it in such a ways that it will aspirate or choke. Embarrassed to express his fears, he may simply not participate in these activities, to which his wife may react by feeling overwhelmed and exhausted by having total responsibility for the child.

New mothers, whether or not they experience an initial period of feeling incompetent, often develop a sense of expertise over the care of their baby. Already less confident in his own nurturing abilities, the young father's confidence takes more hits when his wife corrects (or worse, ridicules) his caretaking skills. Simply redoing a diaper tells Dad, "You did it wrong. You are not competent" to which he typically responds by doing fewer diaper changes, to which she reacts by feeling overwhelmed and exhausted by having the total responsibility for the child, etcetera, etcetera, etcetera.

Power struggles can develop, especially as couples become more comfortable handling their child or more knowledgeable about the syndrome. It is not uncommon for couples to engage in the Right-Wrong Battle, not only about childcare but about many other aspects of the relationship. More on the Right-Wrong battle later.

These unhealthy patterns may continue for years and overlap onto many other areas within the marital dynamic as the child grows or as more children enter the family.

But all it takes to make a move toward change is for one of the couple to do something different.



Typical Stressors on New Fathers	Strategies Toward Change
Lack of rest, lack of sleep.	Nap whenever possible.
Feeling helpless to do anything to "fix" the problem or improve the situation.	<ul> <li>Be involved in child's daily care and routine to extent possible.</li> <li>Ask wife what would be helpful to her and family</li> </ul>
	that you could do.  Learn about syndrome.
	Connect with other fathers.
Not knowing how to care for baby; feeling incompetent; believing he may accidentally hurt the baby.	Be involved in child's care. Ask questions of wife, mother, mother-in-law. Assert desire to participate in child's care. Develop confidence in your child care skills through practice.
Being corrected – directly or subtly - by wife regarding care or handling of baby.	Calmly remind wife that though you may do things a bit differently than she does, you're not doing them "wrong." Assure wife you and baby will do just fine.
Feeling like an "outsider" in his own family.	Ask wife what you could do that would be helpful to her and for the household.
Fear of not being able to provide adequately for family and child's current and future needs; low or loss of income, medical insurance. How to plan for retirement <i>and</i> potential life-long care of child.	Work as team to gather information about estate planning needs. Don't take on whole task alone.
Fear that the marriage will suffer. Feel jealous of wife's attention toward baby. Fear that the closeness couple once felt toward each other will disappear.	Tell your wife when you feel lonely for her attention. Tell her how much you love being with her, even when it's just snuggling on the couch together when the baby goes down. Tell her how close you feel to her when the two of you make love.
	Share your personal hopes and dreams for the future with your wife. Listen to hers.
	<ul> <li>Realize that the couple has changed and will never be as it was before the child, and remind yourself that "different" is not necessarily "bad."</li> </ul>
Blame: Either oneself (especially if child has a deletion or father has prior history), or spouse (especially if child has UPD or if mother has prior drug history), or universe.	Join a support group either live or online. Call other parents on the phone.
	<ul> <li>Remind yourself that there is no "cause" of PWS; it just happened, it's just part of life, and you and your family will do all that you can to create a good family life and build new dreams.</li> </ul>
Feeling sad, hopeless about the future.	Negative thoughts promote negative feelings.     Positive thoughts promote positive feelings.     Force yourself to change your negative thoughts into more positive ones.
	Become a "possibility thinker" and "decide to believe that there is a way and that we will find it – refusing to believe in "impossible."" (N. Martin)
	Create new dreams with your wife and build them together.

Typical Stressors on New Mothers	Strategies Toward Change
Lack of rest, lack of sleep.	Nap whenever possible.
	Don't try to do everything Do the best you can and
Feeling exhausted and/or resentful being primary caretaker	<ul> <li>Ask for help from spouse. Be specific about tasks. Express appreciation for help.</li> </ul>
	Don't criticize/correct spouse's care of child.
	Share thoughts and feelings with others who are good listeners. Limit/eliminate sharing with people who are not good listeners. Before you start the conversation let the person know you are not looking for answers but
Feeling overwhelmed by medical and therapy schedules	Remind self that things will get easier.
	Build in as much time as possible to transition from
Feeling home is "invaded" by therapists, phone calls, well- intentioned relatives who don't understand or "get it."	<ul> <li>Screen phone calls. Schedule times during day to return phone calls, make appointments, etc. Protect the off times by not answering or returning calls.</li> </ul>
Feeling resentful of husband's time away from home, still having a "normal life."	Share thoughts and feelings with husband. Before you start the conversation let him know you are <i>not</i> looking for answers but just a good ear.
	Schedule time away from home when you play and
Lack of social connections used to have; decreased emotional support; feeling of aloneness, isolation.	Schedule some time with girlfriends. Unless it's a matter of life and death don't give dad detailed instructions–based upon your experiences presume he will do a good job keeping his child safe and entertained!
	Connect with other parents who have a child with PWS.  Join a support group either live or online. Call other
Feeling stressed, angry, etc. at relatives or friends who don't "understand" or "get it."	Create a good support network for yourself and husband.
	Remind yourself they may be at different stage of grief place than you.
	Calmly continue to educate about the syndrome.
	Eliminate relationships that are destructive to you or
Blame: Either oneself (especially if child has UPD or mother has prior drug history), or spouse (especially if child has deletion or father has prior drug history), or universe.	Join a support group either in person or online. Call other parents on the phone.
	<ul> <li>Remind yourself that there is no "cause" of PWS; it just happened, it's just part of life, and you and your family will do all that you can to create a good family life and</li> </ul>
Finding "best" therapies/treatments and not being able to afford them.	Become a "possibility thinker" and "decide to believe that there is a way and that we will find it – refusing to believe in "impossible." (N. Martin)
Feeling sad, hopeless about the future.	Negative thoughts promote negative feelings. Positive thoughts promote positive feelings. Change your negative thoughts into more positive ones.
	Create new dreams with your wife and build them to-

#### **Common Stressors on the Established Family**

Too often the unhealthy patterns and habits developed in the early years of the marriage permeate other aspects of the relationship. While it can be difficult to alter negative feelings, resentments, patterns of reaction and protection, it can be done. Even if currently out of sight, intimacy, emotional connection and closeness can be resurrected; indeed must be resurrected for the sake of the marriage and family.

#### **Daily Demands**

As the child continues to grow it can seem that there is never a "resting" period before the next "task" or "phase" needs attention. The demands of daily life, the demands of the child with PWS, and the demands of other children may leave little to no energy to do much of anything at the end of the day. Each spouse may feel completely spent, feeling he or she does the lion's share of the family's work, particularly if one spouse has not yet adjusted to the child's diagnosis and special needs. Couples may find themselves competing with each other for "Most Exhausted" or "Most Stressed" award.

Mothers often feel overwhelmed with having sole or almost-sole responsibility for the child's medical, therapy, educational and social needs, as well as all things related to running the household – cooking, cleaning, laundry, bill paying, repairs, etc. If there are multiple children, these tasks become intensified. If the mother is also trying to work outside the family home, taking care of all of her family's needs can quickly become overwhelming and impossible to adequately manage. Wives may come to believe they can not count on their husbands. There is no such thing as "balance"... everything boils down to levels of priority.

The marital relationship may very well have taken second, third, or fourth position on the priority totem pole, depending upon how many children the couple has.

#### **Support Issues**

Lack of support network becomes glaring. Perceived lack of support from spouse. Lack of extended family involvement and/or perceived lack of support. Differences in support of each set of inlaws. Perceived lack of support from friends. "Weening" out of friends. Chronic grief and exhaustion may keep us focused more upon what we're not getting making it more difficult for us to see our partner's needs or pain.

#### **Financial Issues**

Couples may disagree about how much of the family's resources should be devoted toward child with PWS. Husbands often feel overwhelmed with financial stressors. Blaming and power struggles may become more common.

#### **Childrearing Issues**

Issues related to the couple's individual childrearing philosophies and styles may begin to become problematic. Common amongst families who have a child with PWS is when one parent perceives the other as being too "soft" on the child and compensates by being "tougher" causing problems not only in the marital relationship but in the family structure. Soon the child may learn how to "play one parent against the other."

One parent's emotional reaction to having a child with PWS may elicit the parent's "mercy," prompting the parent not to "push" the child too hard, to just let the child have what he wants, or to cater to the child's "whims" and may be in stark contrast to the other parent's emotional reaction to "push" the child even harder. This dynamic is complicated even more when siblings perceive unfairness.

#### Sibling Issues

Managing the needs of multiple children poses great challenge. Having insight into some common sibling experiences provides parents the opportunity to proactively help their children understand and manage them. Common feelings siblings feel include:

- resentment, guilt, love, jealousy, anger
- a desire to protect
- feeling left out from being told what is going on
- a fear of the disability being contagious or inherited
- embarrassment, compassion, loneliness
- feeling parents love the disabled sibling more
- seeing the siblings disability as a stigma on themselves
- a desire to be "sick" themselves to get attention

#### Younger Children may be at risk because:

- They have a limited understanding of what is wrong.
- They are egocentric thinkers and wonder "Will I catch it?" "What will happen to me?"
- They have magical thinking, i.e. "It's all my fault because I said..." "Did I cause it?" "Will God make it happen to me if I'm bad?"
- Their parents are the most important people in their world, and their parent's attention is often diverted to the disable child.
- In their great desire to please their parents, they may willingly take on too much responsibility.

Pre-Teens and Early Teens are more focused on the following:

They are much more aware of their sibling's differences and much less willing to be different themselves, thus they are more likely to be embarrassed or ashamed of how their disabled sibling looks or acts.

- They feel guilty for various reasons, e.g. because they are healthy and their sibling isn't; because they resent their sibling; because sometimes they wish their sibling was dead.
- They feel isolated, i.e., "My parents don't understand me." "My friends don't understand what I have to go through."
- They are acutely aware of their parent's double standard for their sibling on discipline, chores, achievements, and tolerated behavior.
- They now may resent having to "take care" of their disabled sibling.
- They are the least sympathetic and understanding of their disabled sibling at this age - but that's true in "normal" family situations also.

**Older Teens** often begin to feel more comfortable with themselves and their situation but parents needs to be aware that:

- If the disabled sibling's problems cause too much home disruption and alienation from parents, this is the age when the sibling will "escape" by being away from home a lot.
- Sometimes a parent sees a way to "escape" and expect the teen to become overly responsible.
- They feel a need to "make up" for their disabled sibling by being an overachiever.
- They may question more the justice of why God let this happen.
- They feel a need to protect their sibling from the world.
- They begin to become concerned about who will take care of their disabled sibling if something happens to their parents.

Besides forgiving ourselves for being human, and the siblings also, other steps we parents can take after realizing we have done or said something inappropriate are:

- Acknowledge to your child that you made a mistake
- Let your child vent his/her feelings and admit you also have some of the same feelings regarding your child with PWS, or to the situation the disability creates, i.e., We don't hate Matt for the problems of living with locked cupboards and refrigerator, but we do hate the syndrome at times.
- Do some problem solving with your child regarding how you can both deal with the situation, i.e., We decided that although it wouldn't be fair to Matt to allow Sarah to eat in

- front of him, the compromise is to allow her to snack after he is in bed.
- Find some special time away from all your children, so you can come back feeling more refreshed and less sorry for yourself.

Although it may be hard to believe at this point in your life, when it is all said and done and the siblings are grown, they will most likely become more loving, responsible, and compassionate than the average adult.

#### Strategies to Decrease Stress and Increase Marital Intimacy

When we marry, we often feel an "us against the world" feeling. Marriages that endure manage to maintain that team approach in a variety of ways.

Conflict is not bad for a marriage, in fact it's healthy. Couples in a healthy marriage don't always and don't need to agree on everything. The ways in which couples argue and fight for their position determine the quality of the marriage and the level of safety and intimacy they feel. When the marriage is healthy, so too will be the family structure. Each of the strategies below will help focus your marriage on the four basic characteristics of a healthy marriage – Friendship, Purpose, Connection, Cooperation.

Be Nice! Probably the most basic and yet often most difficult thing to do is to just be nice to our spouse! We may speak to our spouse in ways we wouldn't dream of speaking to a friend or co-worker. So... speak to your spouse as you would a friend or co-worker. Think about your spouse's wants, needs, feelings, ideas as you would a friend's or co-worker's. Retrain and remind yourself that your spouse is your friend, not the enemy and really is on your same side of the family team. When having discussions, see your partner as your friend; it will "soften" your communication. In the beginning it can be helpful to pretend you're being watched by an invisible person and judged on how kind you are to your spouse. Marriages often fail when one or both partners fail to experience or even care about the other's perspective. Be conscious about your spouse's potential thoughts and feelings in response to your words.

Create Positive Thoughts. Negative thoughts promote and sustain negative thoughts and feelings. Positive thoughts promote and sustain positive thoughts and feelings. You really can change your negative feelings by altering your negative thoughts to more positive statements. Force yourself to change your negative thoughts into more positive ones; it will make a huge difference. If at first it feels phony, that's ok. Remind yourself that marriage is not 50/50. Sometimes it's 80/20, sometimes is 30/70. Watch your negative thoughts especially at times when you're the one doing the 80.

Common Stressors on Established Fathers	Strategies Toward Change
<ul> <li>Serving as "bad guy discipline enforcer."</li> <li>Feeling lack of playfulness with child/ren.</li> <li>Disagreements regarding childcare philosophies, spanking v. no spanking, etc.</li> <li>Child's behavioral issues related to PWS increasing.</li> </ul>	<ul> <li>Determine wife's philosophies about discipline. Determine what challenges she perceives re: disciplining child/ren. Work with wife to strategize day-to-day disciplinary methods that she can employ herself.</li> <li>On drive home from work, focus on wife and kids. Initiate ritual where hugs are shared as soon as you walk in, before anything else occurs.</li> <li>Share stores with each other regarding family of origin childrearing philosophies to gain deeper understanding of each other. Work toward discipline compromises.</li> <li>Connect with other parents re: strategies.</li> <li>Tag-Team Approach</li> </ul>
Feeling like an "outsider" in one's own family. Feeling "not enough;" not enough for wife, not enough for family.	<ul> <li>Get more information about daily activities of family members.</li> <li>If important event occurs, call to follow up and see how it went.</li> <li>Call home during the day just to say hi.</li> </ul>
<ul> <li>Fear of not being able to provide adequately for child and family.</li> <li>Fear of spending too much family income on child with PWS which precludes care of other children or other family goals. Fear of how to plan for retirement and potential life-long care of child.</li> </ul>	Don't take on whole burden of family's financial stability by yourself. Talk with your wife about your concerns. Create a budget with your wife. Get her input on where family can reduce expenses.
Disagreement regarding treatment philosophies i.e., growth hormone, sex hormones, supplements, orthotics, etc.	Do as much research as possible with professionals and other parents. Explore in depth spouse's thoughts, experience, objections, concerns, etc. Work toward compromise if possible.
<ul> <li>Fear marital relationship is suffering. Feel unsupported by wife.</li> <li>Fear closeness couple once felt will disappear forever. Want a vacation without child/ren but cannot take one.</li> </ul>	Share your wish to feel closer. Research respite options.  Plan an evening date. Or plan a date in your bedroom after the kids are in bed.
Blame: Mother "too soft" or "too hard" on child.	<ul> <li>At appropriate time, calmly share your observations with wife, as well as how her style of discipline (or lack thereof!) affects you. Share what you'd like to see done differently.</li> </ul>
• Guilt	Don't try to "make up for" or overcompensate.
Not enough time alone enjoying activities or hobbies once enjoyed. Feeling emotional and/or socially isolated.	Make arrangements with your wife that allow you to have some alone time or time to do a preferred activity. Get back in touch with what your preferred activities (i.e., hobbies) are!
Knowing child has daily challenges and feeling unable to "do" anything to "fix" it.	Remind yourself that by providing a stable, loving home you are doing the <i>very best</i> for your child.
Blaming spouse for our sadness, grief, fear, etc.	Blame helps us manage our sadness, grief, fear, etc. Remember your spouse is simply a human being who has vulnerabilities, fears, patterns of reaction, etc. Neither is infallible. Shortcomings do not make or break the marriage.

Typical Stressors on Established Mothers	Strategies Toward Change
Blame: Father "too hard" or "too soft" on child.	<ul> <li>Speak privately with spouse about your concerns. Determine their perception of and motivation for being "hard" or "soft" on child. Explore your husband's goals/dreams for his child.</li> <li>Take parenting class together or consecutively if child care is an issue.</li> </ul>
Feel lonely, isolated, neglected, abandoned by spouse.	<ul> <li>Work with husband to find/create trustworthy babysitter and enjoy some alone time with husband.</li> <li>Schedule play time with girlfriends when Dad does the dad thing. Don't undermine husband's caretaking abilities. Express appreciation for his care of kids!</li> </ul>
Feeling completely spent. 24/7 giving to family members (and others) leaves nothing left for oneself. Resent partner who appears to have "normal" daily life, free of concern for child's moment-to-moment needs.	Ask for more help from husband or others. Be specific about tasks you'd like help with. Express appreciation for help.
Being primary caretaker of child, feel more tired, more stressed, have less ability to listen patiently, supportively or warmly to partner.	<ul> <li>Tell you husband when you're feeling irritable or impatient.</li> <li>Ask him to be more patient with you.</li> <li>Tag-Team Approach</li> </ul>
Not enough time alone or enjoying activities once enjoyed.	Make arrangements with your wife that allow you to have some alone time or time to do a preferred activity. Get back in touch with what your preferred activities (i.e., hobbies) are!
<ul> <li>Feeling overwhelmed with daily needs of child/ren</li> <li>Feeling overwhelmed with household chores.</li> </ul>	<ul> <li>Change negative statements to positive ones. Fake it if it feels unnatural.</li> <li>Determine if family budget can afford housekeeper.</li> </ul>
Feeling hopeless about the future: marriage, child, family, etc.	Assess level of depression: Comes and goes? Higher than usual? High level all the time? Share feelings with husband. May be helpful to seek counseling.
Blaming spouse for our sadness, grief, fear, etc.	Blame helps us manage our sadness, grief, fear, etc. Remember your spouse is simply a human being who has vulnerabilities, fears, patterns of reaction, etc. Neither is infallible. Short-comings do not make or break the marriage.

Depression is an inward-looking, spiraling malady; the more we feel depressed, the more drawn in we become to our own thoughts and feelings. The more we focus on our own sad thoughts and feelings, the more depressed we become. To break this cycle, work to shift your focus from your own disappointments, losses, etc. and force yourself to think and wonder about your spouse's disappointments, losses, etc. Depression is also quite biochemical. It may be necessary for your health and the health of your family to seek treatment and/or medication to help relieve your level of depression if it begins to interfere with your ability to do the things you need to do on a daily basis.

Express Anger Appropriately. Be careful when expressing anger. You can't unring a bell. Accusations or character assignations said in anger can linger for years and insidiously undermine intimacy. Saying "I'm sorry, I really didn't mean it" does not unring the bell. Appropriate expression of anger is healthy... "Ohhhh, I'm so angry at you. I feel completely taken for granted and ignored. I have asked you at least a hundred times to pick up your hair off the bathroom floor, and you don't do it. I don't want to feel so tired all the time. I want you to pick up your hair from the floor!" NOT: "You are such an inconsiderate \*&!%!"

**Find the Grain of Truth** in the other's complaint or statement. It is always difficult to be "accused" of being/doing something which is why we automatically defend ourselves against such statements. Hearing "You always" or "You never" automatically sets up the need to defend oneself against what's coming and keeps us from hearing the content of what's being said. Finding the "grain of truth" in our spouse's statement or accusation, acknowledging it, and then doing something about it will help.

How to find the grain of truth? First, presume there is a grain of truth. Second, acknowledge that part which is true. And third, if you really can't see the grain of truth, ask questions about why your spouse thinks or believes what they do and LISTEN to the response.

**Eliminate the Right – Wrong Battle.** Couples often get into never-ending battles because the fight assumes a Right-Wrong position: If I'm right then that proves you're wrong. If you're right, then that proves I'm wrong. No one wants to be wrong, so we argue our side without taking into account anything our spouse offers. Getting out of the Right-Wrong battle will decrease hostility. How to get out of the Right-Wrong battle? Change your thinking from "That's Wrong" to "That's Different." Ask open-ended questions. Why does your partner think / behave that way? What contributes to your partner's belief? LISTEN to the response. Look for the grain of truth in the argument.

High stress can develop into a competition of "My stress is greater than your stress" or "you don't understand my stress" or worse, "you don't care about my stress." Not only is this a Right-Wrong

battle, it's also negative thinking.

Ask for what you want clearly and directly. "I" statements really do work. "I" statements help you get clearer on what you're wanting/needing/missing and help you ask for it without blame. Example of unclear expression of want or need: "You are so selfish. I can't believe you just watched me fold all that laundry and not once did you even offer to help." Example of clear expression of want or need using an "I" statement: "I'm feeling stressed tonight. I would really appreciate your help folding the laundry. If we do it together, we'll get finished faster and have time to cuddle/play/make love!"

#### Suggested Specific Techniques to Practice and Incorporate

- Create Couple Time whether it be in bed at night, or over coffee on a weekend morning, or afternoon.
- Present a united marital front. Don't fight in front of kids; don't overrule the other parent in front of the kids; support your spouse in front of your parents; don't gossip about your spouse to others.
- Reminisce together about your history: your dates together, what you liked about each other, why you fell in love, your wedding, your first house, your child's birth, your hopes and dreams for the future, etc. Look at photos together.
- Remind yourself of your spouse's positive characteristics.
   Remind yourself why you love your spouse.
- Build in couple and family play time as often as possible.
- Share experiences / stories about the pregnancy, the stress experienced after the birth, the stress currently experiencing.
- Practice really listening to your spouse's stories. Ask questions, learn more about your spouse.
- Talk daily about each other's daily events, whether big whopper events or mundane minutia. It will bring you closer together.
- Share stories about work and what the kids did today.
   Don't criticize. Don't offer solutions (unless asked for).
- Be aware of what you want / need. Ask directly and clearly for what you want / need. "I just want you to listen" or "I want your opinion."
- Request spouse's opinions and input. Don't ask for an opinion and then discount or ignore it.
- Presume your spouse's competence.
- Presume your spouse has your and the family's best inter-

est at heart. If you believe he/she doesn't, presume there's too much stress getting in the way of his/her compassion and work to help reduce it.

- We all have about the same level of emotional competence as our partner. We may be more competent in one area and our spouse more competent in another, but overall we tend to pick a partner who matches us. Believing ourselves "better than" our spouse is an indication the marriage is off track.
- At times of anger or emotional distance, remind yourself that you love your spouse, remind yourself why you first fell in love with your spouse, and remind yourself why you love your spouse now.
- Spend time doing chores together, side by side washing dishes, gardening, taking a walk around the block, doing an art project. No talking necessary. Just be together.
- Time together doesn't have to cost money. Do a family picnic or camp out at the park, the beach, in the woods, or in your back yard. Break out the camera so it feels like a vacation.
- Don't be afraid to talk about the kids on one of those rare dates!
- Work together to create at least 30-60 minutes alone with your spouse before going to bed.
- Go to bed with your spouse more nights than not.
- Eat dinner together as a couple or a family more nights than not.
- Screen phone calls. Schedule times during day to return calls, make appointments, etc. Protect the off times by not answering or returning calls.
- Negative thoughts promote negative feelings. Positive thoughts promote positive feelings. Force yourself to change your negative thoughts into more positive ones. It will make a huge difference.
- Create new dreams with your spouse and build them together.

# **All I Really Need to Know I Learned In Kindergarten** by Robert Fulghum

Most of what I really need to know about how to live and what to do and how to be I learned in kindergarten. Wisdom was not at the top of the graduate-school mountain, but there in the sandpile at Sunday School. These are the things I learned:

Share everything.

Play fair.

Don't hit people.

Put things back where you found them.

Clean up your own mess.

Don't take things that aren't yours.

Say you're sorry when you hurt somebody.

Wash your hands before you eat.

Flush.

Warm cookies and cold milk are good for you.

Life a balanced life – learn some and think some and draw and paint and sing and dance and play and work every day some.

Take a nap every afternoon.

When you go out into the world, watch out for traffic, hold

hands, and stick together.

Be aware of wonder.

References:

Fulghum, R. ((1991) All I Really Need to Know I Lerned in Kindergarten: Uncommon Thoughts on Common Things, lvy Books, New York, NY

Gottman, J. and Silver, Nan (1999) *The Seven Principles for Making Marriage Work*, Three Rivers Press, New York, NY

Leick, N. and Davidsen-Nielsen (1991) *Healing Pain*, Routledge, New York, NY.

Martin, N. (2004) Strengthening Relationships When Our Children Have Special Needs, Future Horizons, Arlington, TX

Perske, R. (1981) *Hope for the Families*, Abingdon Press, Nashville, TN

Slap-Shelton, L., *The Phases and Tasks of Grief Work*, Article.

#### Quiz

Play this game together in the spirit of laughter and gentle fun. The more you play, the more you'll learn about your spouse.

**Step 1**: Each of you take a piece of paper and pencil and together, randomly decide on twenty numbers between 1 and 60. Write the numbers down in a column on the left-hand side of your paper.

**Step 2:** Below is a list of numbered questions. Beginning with the top of your column, match the numbers you chose with the corresponding question. Each of you should ask your partner this question. If your spouse answers correctly (you be the judge) he or she receives the number of points indicated for that question, and you receive one point. If your spouse answers incorrectly, neither of you receives any points. The same rules apply when you answer. The winner is the person with the higher score after you've both answered all twenty questions.

- 1. Name my two closest friends. (2)
- 2. What is my favorite musical group, composer, or instrument? (2)
- 3. What was I wearing when we first met? (2)
- 4. Name one of my hobbies. (3)
- 5. Where was I born? (1)
- What stresses am I facing right now? (4)
- 7. Describe in detail what I did today or yesterday. (4)
- 8. When is my birthday? (1)
- 9. What is the date of our anniversary? (1)
- 10. Who is my favorite relative? (2)
- 11. What is my fondest unrealized dream? (5)
- 12. What is my favorite flower? (2)
- 13. What is one of my greatest fears or disaster scenario? (3)
- 14. What is my favorite time of day for lovemaking? (3)
- 15. What makes me feel most competent? (4)
- 16. What turns me on sexually? (3)
- 17. What is my favorite meal? (2)
- 18. What is my favorite way to spend an evening? (2)
- 19. What is my favorite color? (1)
- 20. What personal improvements do I want to make in my life? (4)
- 21. What kind of present would I like best? (2)
- What was one of my best childhood experiences?(2)
- 23. What was my favorite vacation? (2)
- 24. What is one of my favorite ways to be soothed? (4)
- 25. Who is my greatest source of support (other than you)? (3)
- 26. What is my favorite sport? (2)
- 27. What do I most like to do with time off? (2)
- 28. What is one of my favorite weekend activities? (2)
- 29. What is my favorite getaway place? (3)

- 30. What is my favorite movie? (2)
- 31. What are some of the important events coming up in my lie? How do I feel about them? (4)
- 32. What are some of my favorite ways to work out?(2)
- 33. Who was my best friend in childhood? (3)
- 34. What is one of my favorite magazines? (2)
- 35. Name one of my major rivals or "enemies." (3)
- 36. What would I consider my ideal job? (4)
- 37. What do I fear the most? (4)
- 38. Who is my least favorite relative? (3)
- 39. What is my favorite holiday? (2)
- 40. What kinds of books do I most like to read? (3)
- 41. What is my favorite TV show? (2)
- 42. Which side of the bed do I prefer? (2)
- 43. What am I most sad about? (4)
- 44. Name one of my concerns or worries. (4)
- 45. What medical problems do I worry about? (2)
- 46. What was my most embarrassing moment? (3)
- 47. What was my worst childhood experience? (3)
- 48. Name two of the people I most admire. (4)
- 49. Name my major rival or enemy. (3)
- 50. Of all the people we both know, who do I like the least? (3)
- 51. What is one of my favorite desserts? (2)
- 52. What is my social security number? (2)
- 53. Name one of my favorite novels. (2)
- 54. What is my favorite restaurant? (2)
- 55. What are two of my aspirations, hopes, wishes?(4)
- 56. Do I have a secret ambition? What is it? (4)
- 57. What foods do I hate? (2)
- 58. What is my favorite animal? (2)
- 59. What is my favorite song? (2)
- 60. Which sports team is my favorite? (2)