

'No Magic Pill'

We see it ALL the time ~ take this pill or use this machine and you will lose 30 pounds in one week, feel more energy and be happy, or look and move like a well-conditioned elite athlete. Sounds good...BUT...**life doesn't work that way!**

Even though we may know in our heads that those things won't work overnight or over the long haul, we're hoping we're wrong and that they WILL work and make our lives easier or more fulfilling. Sometimes when things get difficult we grasp for just about anything to ease our pain ~ whether it be physical, mental, emotional or spiritual pain.

The same principle applies to our situations as FOD Individuals/Families dealing with a chronic disorder. It would be nice if once we knew which disorder we were dealing with that our child(ren)/we could take a pill and everything would be cured and episodes would never occur. Unfortunately, magical thinking only complicates how we, and our children, might practically and emotionally deal with the disorder.

As much as we wish it to be true, there is **NO MAGIC PILL** or 'one size fits all' prescription when it has to do with losing weight, gaining muscle or being happy ~ just as there is no one symptom description or treatment protocol that covers ALL FODs for ALL children/adults. There may be some common symptoms/treatment suggestions, but you can't make a blanket statement that ALL present the same way and should be treated the same way. And that goes not only for the practical aspects of medically dealing with these disorders but also for how our children/we emotionally cope with them on a daily basis and through the years. There is not just one way that works for everyone. There are too many factors and characteristics that are unique to EACH individual and family to make the bold and totally unrealistic assumption that what works for one will automatically work for another and will continue to work over time.

So if we can't 'just do it' all the same way year after year, then where does that leave us? **What CAN we do, as parents of an FOD child or as an adult FODer, in order to cope with these disorders over time and how can we help our children with constructive suggestions when they have uncomfortable or strong feelings or behave in a difficult way and don't know where and how to channel their energies?**

First of all, when you/your family get an FOD diagnosis, **acknowledging and understanding** that many of the assumptions you might have had about how your life SHOULD BE and how every child born to your family SHOULD BE that so-called 'perfect' baby are shattered. And **that shattering most definitely will touch every aspect of your being ~ emotionally, physically, cognitively, behaviorally, socially and spiritually.**

Yet that **shattering of assumptions** does not automatically mean that life is going to be miserable. Within the context of the bigger picture, it **presents us with the OPPORTUNITY to make some changes** ~ not only in our own lives but in our family's lives. If any of us stayed in that shattered state, I wouldn't be writing this right now and you wouldn't be reading it! So...**we ALL have a CHOICE.** Unfortunately, for some, that choice includes denial or running away from the situation, which doesn't help our children/ourselves in the long run. For most, **that choice will hopefully entail putting**

those fractured pieces of our hearts back together in a new and different way, yet also in a way that helps us to positively and proactively move forward in life and to **help our children KNOW and BELIEVE that they are just as SPECIAL as they are ~ with or without an FOD!** And also for us to KNOW and BELIEVE that we are good persons/parents and NOT horrible people for being carriers of these rare disorders!

Going back to the weight loss scenario, cutting calories and certain types of foods is not the only focus for making that change ~ it also takes exercise, relaxation/meditation, motivation, lots of water, and being around others that will support you and not sabotage your program, as well as many other factors to really help in the process if it's going to be a healthy process. If you chose to cut out eating completely that would not only be self-destructive and dangerous, but it would most likely cause you to gain even more than what was lost when you begin eating again. So **working with all the factors as an important part of the whole picture** will ultimately make an impact on your goal of seeking a healthier lifestyle and body weight/image. The same goes for dealing with **FODs ~ seeing them in a multidimensional way and not just in one way will benefit ALL in the family.**

A challenge for all of us is learning how to work WITH these disorders and not AGAINST them, and work with them as an individual and as a family. A first step for many of you (probably after being THRUST into chaos after the diagnosis!) was becoming part of this Support Network where you KNOW that you are NOT alone in your struggles and in taking on all these challenges! It may not be your typical support group in that we don't meet face to face, but it's **the immediate connection that we make with other FOD families experiencing similar concerns that makes this Group 'work!'**

In taking on the challenge we are **acknowledging** that our child(ren)/we have a rare genetic disorder that has short- and long-term ramifications in ALL dimensions (i.e. medical, emotional, mental). Acknowledging that fact propels you to learn more about FODs so all will **understand** (although my brain can only hold a small amount of biochemistry!) what's happening metabolically. Yet it may also give rise to many fears about the present, as well as what the future may hold. Gaining medical and practical information and utilizing it over time may alleviate some of those fears and the stress that often accompanies those fearful thoughts. A key to coping with these disorders is to **be DETERMINED to NOT have it break your spirit or your child's spirit.**

One way of activating your spirit is to **embrace and constructively express ALL of your feelings** such as fear, guilt, anger, frustration, vulnerability, and grief. Feelings just are ~ they are not good or bad ~ what CAN be bad is what happens when feelings aren't expressed. Trying to suppress them will not only give your children the wrong message about dealing with emotions, but they will most likely come out in other not-so-positive ways at some point in time (i.e. acting out, non-compliance, use of substances to numb themselves). Help yourselves and your children by learning to **normalize and validate your feelings and thoughts** in order to be able to go with the ups and downs and the flow of life's difficult challenges.

It's important to help our young children to **label their feelings**. They may not be able to articulate exactly what they are feeling inside (depending on their developmental and cognitive levels). So having them draw a picture or play with puppets or toys may help

you and them get a feel for what they are experiencing. Encouraging them to tell you about their picture or 'talking' through a puppet will further uncover specific feelings.

For older children, it may be even more of a challenge since some adolescents don't want to talk directly about what they are feeling. Sometimes doing an activity with them such as taking a walk, listening to music, watching a show/movie, playing catch etc. can be a good way of connecting. Yet, telling them to just 'snap out of it' isn't going to help the situation. They are not only medically dealing with their disorder, they are dealing with the normal concerns and learnings of adolescence and that can oftentimes be a rocky ride.

LISTEN to what they have to say and WATCH their behavior and try to reflect their feelings and thoughts back to them without telling them that they shouldn't feel the way they are feeling (i.e. angry, sad). Many times there are feelings underneath that anger and sadness, possibly a fear or sorrow that they might not be accepted by their peers because of their medical concerns and restrictions in activities or foods...or that they might have some embarrassing episode in front of others...or that they may never have the opportunity to run or play a sport. These are all REAL to them and they **need to be normalized, validated and expressed in constructive ways.**

Being able to do these things gives us a sense of control over what we might think is a totally uncontrollable and stressful situation. Actually, it's the holding in and down of our emotions that makes the situation even more chaotic/stressful. So **MODELING the "Naming, Claiming, Framing, and Taming** (meaning expressing constructively)" **of our feelings and thoughts** (terms that I read years ago in a *Family Networker* journal) is vital to actively coping with these disorders in a HEALTHY way.

In past articles I have mentioned a variety of ways to express emotions and deal with stress such as journaling, write stories or poetry, exercise, listen to music, hit a pillow, and volunteer, just to name a few. Any of these can be done alone or as a family. Expressing emotions symbolically can also be 'healing,' such as lighting a candle on special memory days or holidays or volunteering your time/money/toys at a children's hospital. The important thing to remember is to **find ways that work for you and your family.**

Another important aspect of healthy coping is being **ASSERTIVELY PERSISTENT** when running into obstacles, whether it be a lack of answers/diagnosis, insensitivity of patronizing people that tell you to stop being overprotective and go home to enjoy your child while you can (that HAS been said to several of our families!), or difficulty in obtaining needed services at school/home/work for your child/self. It's a FAMILY AFFAIR when receiving an FOD diagnosis and many **adjustments** (i.e. meds, diet, specialist appointments, decision whether to work or stay home, finances/insurance, making sure non-affected sibs get their needs met too) need to be made inside and outside the family ~ so **NOT GIVING UP** is imperative to making those adjustments and making them manageable for your family situation. Additionally, **open communication** with other family members and professionals is vital. If you don't feel you are getting what your child/you need, then seek out other emotional support or medical help.

Just because we know there is '**NO MAGIC PILL**' or quick fix doesn't mean we give up hope ~ **there IS HOPE** ~ hope that as individuals and families we will find meaning in

our life challenges, hope that researchers will develop more sensitive/effective diagnostic tests so EARLY DIAGNOSIS and TREATMENT can begin before a severe episode unnecessarily takes another child's life, hope that our children/we will **INTEGRATE** these disorders into their lives as they get older, hope that they also learn that **they are NOT their disorder and that they grow to be who they are to be**, and hope that those families that may experience a death in the future have the strength and support to work through their difficult times ahead.

Even though many still have not heard of these rare disorders, it is MY hope that through our efforts as individuals and as families within our local communities and even around the world, more professionals will become aware of and knowledgeable about FODs so that each child/adult with an FOD will receive the earliest diagnosis and most effective treatment so they can live a **full and meaningful life!**

A goal for the new millennium may be to live EACH day to the fullest because none of us knows for sure how long our mission on earth will be. Strive to **Love, Live, Work, and Play with PASSION and PURPOSE!** There is '**NO MAGIC PILL**' to make any of that happen easily ~ but you can bet **when they are done based in LOVE and COMPASSION, life will be so much RICHER!**

Peace, Joy and Love in 2000 and beyond...

Deb Lee Gould, Director, FOD Family Support Group
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