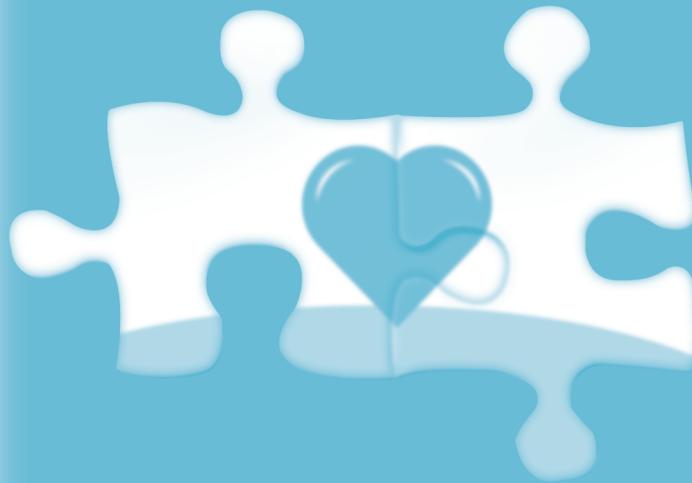


After the Autism Diagnosis

Staying Connected as a Couple



How does a couple stay connected and strong once autism has become part of their world?

by Mary Romaniec

When families receive the autism diagnosis a period of mourning follows. Parents describe their grief as very much like that of the loss of a child. This may sound like a cliché, but it's true. In many ways, it is a loss. The child we imagined and the life we dreamed for the family is now replaced with a huge void of uncertainty.

The divorce rate in couples who have a child on the spectrum has been suggested to run as high as 80%. Personally I have not seen that level of divorce but I have witnessed virtually every couple whose child is diagnosed with autism go through severe difficulties. I don't believe even seasoned marriage counselors are fully aware of the complex stressors these parents face, that is unless the counselors have an autistic child themselves.

In my conversations with parents I mentor and in ordinary conversations with the families on this autism jour-

ney with me I have noticed a reoccurring pattern couples go through once their child is diagnosed. I call this the six **Grief/Acceptance** stages. It follows closely the grief model developed by Elisabeth Kübler-Ross M.D of the five stages a dying or grieving person experiences while accepting death: Denial, Anger, Bargaining, Depression and Acceptance. However, as in many other ways, autism is unique unto itself, and the stages that parents of a spectrum child go through are not quite the same as Dr. Ross' model.

Compounding matters, each person goes through these stages at different

times, and at different speeds. This, in itself, is a catalyst for much of the stress I see developing between the couple. Although I am not a professional counselor or psychologist, I am a mother of a recovered autistic child, a mother to two typical children and a wife to a wonderful

husband. And our own personal experience definitely mirrored the same pattern I have seen in other couples.

THE SIX STAGES OF GRIEF/ACCEPTANCE

FEAR. Not just fear, but absolute terror is commonly felt because of the global erosion autism can bring to the family. Fear can seep into every aspect of the marriage and the family unit: fear of the unknown, fear of the child's and family's future, fear of your own ability to handle the physical and emotional stress, fear of your ignorance of what

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autism is, fear you will fail yourself, your spouse and your child on any and all fronts. At the moment of diagnosis, life changes.

I often hear from couples where one partner gets stuck in this stage, and it's more often mothers than fathers. Men want to act; women typically have to “process” and unfortunately, autism can be an endless loop in which it is easy to get stuck. Not just stuck, but paralyzed from making decisions. Unfortunately the nature of autism requires that parents quickly begin educating themselves about autism and treatment options and make decisions about their child's future – at least his or her immediate future. Yet, I have often talked with frustrated fathers who want to pursue dietary and biomedical intervention but the mothers are afraid to move forward for fear of making a mistake. Family backgrounds and core personal beliefs affect to what extent fear immobilizes a parent in this stage. And, while this one is the toughest to overcome, get through it you MUST. There are five other stages to go through before real positive changes begin to happen.

ANGER. Once the fear begins to dissipate, anger sets in and it is spewed in a variety of directions. You will feel angry at circumstances in your life that are a direct result of the child's autism, angry at what might have caused the autism, angry at yourself/your spouse if you think either of you ‘did something’ that may have caused the autism. You may even feel angry at your child, which is often the hardest feeling to bear. You will also feel angry with people who do not take the time to tell you what to do next. I see huge amounts of anger directed at the medical community for not noticing the symptoms of the child's behavior sooner or for mitigating a parent's concerns. This was very real for my family as I realized how much information I was going to have to find on my own.

DENIAL. This is commonly the stage I see many fathers get stuck in, and it can be a vitriolic sort of denial. I hear from mothers across the country who experience their husbands' verbal abuse, who share tears of isolation and loneliness and feel they are fighting the battle for their child alone while the husbands go through, or freeze, at this stage. It can take many months, if not years for some men to process through their child's diagnosis. It took my husband a full year and a half to even say the word “autism”.

BARGAINING AND/OR GUILT. In this stage the couple tries to mitigate the disorder by figuring out what they will or will not do in order to cope. Will they pursue diet, biomedical treatment, ABA behavior therapy, a home-based program, supplements or just plain old pharmaceutical options?

Virtually every decision or course of action is met with a bargaining mentality (if I do this then I won't need to do that) or guilt (I need to do all of this or I am not doing enough). This is the stage in which couples can end up divided into two camps as to treatment for the child. In many cases, one partner is passionate about a particular treatment while the other is either opposed to it, or is still caught in Stage #1 and unable to make a decision either way. It is in this stage that I see couples start to drift away from each other, when fights begin or intensify to new levels of disagreement.

ACCEPTANCE. Acceptance comes in different forms for different couples. For some couples it comes bit by bit. They get to a point that the decisions they have made, the routine they have established and the regular improvements they have seen in their child result in acceptance of autism as part of their family and their lives. Their experience has taught them that they can handle it in some sort of orderly fashion. Other couples seem to experience moments of revelation where they experience in mind and heart that autism is just one aspect of their child, and their family, that the disorder is happening *to the child*, and their role in being their child's loving guide becomes clear. However acceptance happens, hopefully they have reached this point together.

RESOLVE TO OVERCOME. The final stage I witness in many of the newly diagnosed families I mentor is a resolve to overcome. In most cases, these are parents who have devoured the wealth of information that now exists about autism, have gone to the latest autism conferences and networked with other parents who have been successful in their struggles with autism. These parents actually find HOPE in the midst of the information. They hear about children recovering from autism and resolve to do whatever it takes to create the widest range of opportunities for their child, based on his own individual characteristics and needs, to learn and grow. At this point they are ready to begin taking the steps toward helping their child to recover, or achieve his highest level of functioning possible.

DISCOVERING WHAT WORKS

What is remarkable to me as a parent mentor is how radically our progression through these stages can vary. Some

parents fast forward through them in lightening speed; others can take years to go through a single stage. And therein lies perhaps the biggest challenge for a couple: how to stay connected on the journey, respect each other being at different points of acceptance, and yet work effectively together for the benefit of the child. Unfortunately what I see often is that couples get stuck in various stages and precious time is lost. Or although both are committed to the child, they reach an impasse. Any one of these six stages can interfere with parents coming to agreement on one or more aspects of caring for their child with autism. But I also have spoken with couples who although united in their desire to help their child, wanted to move forward from different angles. One parent wants to aggressively pursue one treatment while the other wants to pursue another. They both want the best for their child but they are adamantly convinced their ideas are the only ones to benefit their child. Or worse, they are flat out worried their partner's choice will actually harm the child. If there ever was a time to compromise and negotiate it would be at this cross-road; unfortunately, not all parents reach accord. And sadly, it is the child who suffers.

Couples find themselves united or divided in working through autism based on several influences they personally bring to the interaction. One factor that contributes to "togetherness" is their own communication and interaction style. Are they naturally argumentative or competitive with each other? Is one more dominant over the other? Does one often play the martyr in their marriage? Or are they naturally in sync with each other's needs, fears and anxieties? In virtually all relationships in which a child is diagnosed on the spectrum, roles will change in some way or reverse entirely. Partners who can consciously work through the rocky times often find a new way of communicating and relating to one another. While their roles in the marriage are forever changed, many find it to be for the better.

Over the years of talking with couples, and with women in particular, I have shared with them some funny anecdotes of a 'strategy' that quite simply WORKS to bring couples to the same place of acceptance and resolve, but perhaps a bit quicker.

At the 2005 DAN Conference in Boston I happened to be part of a parent panel. A woman stood up and asked a question about how to improve her marriage through this autism journey. I quickly took the microphone and offered a series of anecdotes that had the audience cheering and laughing. The positive reaction of the audience propelled me to offer these same suggestions to other couples as a means of working through the various stages together, and on a more even pace.

What I shared at the DAN conference, on the subject of improving communication in the marriage during this time of crisis, follows.

"I got a call from a mom I was mentoring on diet and biomed. She was FURIOUS at her husband for feeding her

son gluten foods that caused his bad behavior the entire day. She told me that when her husband got home she was going to make his night as miserable as her day had been. I told her to stop and rethink that idea. Instead of launching an attack on him why not put the kids to bed early and give him a night he would not forget. And then in the morning gently mention to him how much you need his help to maintain her son on the diet, etc. Hmmm, wonder what would get his attention more - nagging or good sex?

Mom was surprised to hear me suggest this, because being intimate with her husband was the furthest thing from her mind. She was MAD. So I talked to her further about needing her husband on her side, not fighting her or tuning her out. She needed to get his attention in a way he would remember. She called me the next day to say it worked and her husband swore to help with the diet more.

Then she asked for advice on how to get him to help her with other aspects of their relationship and their child's program (more input from him, going to conferences with her, attending IEP meetings, etc.). As with many other husbands in the autism community, he was feeling neglected by his wife going into hyperdrive to help their child. In fact he even said "You don't pay attention to me any more." Sound familiar? So I told her she needed to REALLY get his attention during a weekend away they had planned. I suggested she not talk about the kids Friday night or Saturday night because he was to be her total focus. However, on Sunday morning at breakfast she was to gently give him her list of things she needed from him. Needless to say it worked and he was definitely a happy man too. He even came to one of my seminars on GFCF diet shortly after.

So this same type of advice has been passed along to many other women and several have emailed or called to say "It worked! He's on board!" I even had a woman recently email me to say she was off to take a shower. She needed to get her husband on board with something and knew what would best help get his attention.

Another woman told me she got her husband to come to a DAN conference with her by promising the hotel room would be put to good use. He got a lot out of the conference in more ways than one. He then began to help with other things with the kids when they got back, including joining her at IEP meetings.

Bottom line, many husbands are in a level of emotional shutdown. Women tend to handle autism differently. We spring into action, call our friends for support and begin lots of research. The guys cannot necessarily do this right away. They need to know they are supportive of us, but we tend to push them away because we get angry at them for them not being at our same level of crisis mode.

So, as hard as it may be I suggest to women to go against your 'ticked off' instinct and instead go in the direction of meeting your husbands' needs. Most men will more than jump

at the chance to be supportive of your needs after they have been “replenished emotionally” so to speak. It may take time but at least the effort is being made to stay connected. Autism is a difficult thing for any couple to endure. Those that come through this are usually stronger for it. My husband and I are definitely in that category. And I am one of those who “got his attention” first in this manner. He is now my biggest fan and greatest supporter. And our son is recovered thanks to our combined efforts.”

After I related this story at the DAN conference, two women came up to me laughing and crying at the same time. One said she realized how much harder she had made it on herself by fighting her husband all the time and pushing him further and further away. Another woman came up with her smiling husband in tow. She too acknowledged she had been “doing it wrong” and planned to change things that very night. Her hubby was very happy to hear this. And several women stopped me in the hallway at the conference to say “You are so right!”

Moms reading this article, listen up: I got an email from a woman wondering if she could talk to her husband right after the fun evening (ya’ know, when he is more apt to want to sleep?). Ladies, you have to realize this man probably has no respite from the worry or the crisis and part of this strategy is to give him that, so you will receive help from him in return eventually. I told her NO and to back off on any demands for a bit. And then when she did ask for something make sure it was concrete, something specific he could do so that he feels he is beginning to meet your needs and you are grateful.

But what if it’s the mom who is having the tougher time getting through the stages? Dads reading this: I suggest to the man to move forward anyway and gently bring her along with an air of confidence, not belligerence. Treat her like a girlfriend and

remind her of why you married her in the first place. She’s feeling fragile right now and unsure of herself. There is definitely something positive to someone else taking charge and alleviating the burden she feels if she is not ready to cope with decisions at the time. She will take a more active role as she gains her own confidence in the process and in the support she’s receiving from you.

In the end, the goal is NORMAL in our families – however we define that word. How do we carve that out every day of our very UNnormal lives? For me it was remembering why I fell in love with my husband in the first place. He can find humor in the most absurd of situations and I am his best audience because I laugh at all of his jokes. My daughter had to also be reminded how special she was to us and we ensured she was treated to special moments alone with both her dad and me. And as a family we made it a point to bond together in the simple and even mundane moments. But it all began with my bond with my husband.

Nothing can totally prepare a couple for the “for better for worst” portion of their vows when it comes to receiving the autism diagnosis. But for those couples who do manage to forge through this crisis and remain united, the odds are truly in their favor that they will weather any other storm that lies ahead.

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