

a parent's journey to acceptance

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an article in the American Association of Plastic Surgeons newsletter stated that in the United States a child is born with a cleft lip or palate every 75 minutes. The article also stated that nearly two out of every 1,000 infants born will have some type of craniofacial birth defect. Every day, new parents are introduced to the reality that their child may not just look different but may have physical, emotional and intellectual developmental delays.

The Dream vs. the Reality

As the social worker for the Miami Children's Hospital Craniofacial Team, as well as the Dan Marino Center for children with autism, I am referred to parents whose children have been newly diagnosed with a craniofacial anomaly. Often at the initial meeting with parents, I can sense uncertainty and despair.

I look into eyes that ask "How did this happen? What in the world do we do now?" The visions of their children did not include receiving the news that their child has a cleft lip and/or palate or craniosynotosis.

All parents hope for a non-complicated pregnancy and a healthy birth. Even when genetic testing and ultrasounds indicate with enormous certainty that a child will be born with some deformities, many parents still hold fast to a little seed of hope for the possibility that the medical team was incorrect in their diagnosis.

Stages of Grief

For many parents, learning that their child has a "syndrome or disorder or craniofacial anomaly" is as traumatic as being told that their child is terminally ill. They often grieve for the child they thought they were going to have.

Five Significant Stages of Grief

1. Shock
2. Denial/Anger
3. Guilt/Bargaining
4. Sadness/Depression
5. Acceptance

Just as if there was an actual death, parents experience the five stages of grief. This process is not experienced in a specific stage order. From my experience as a social worker, I have observed that the stages of shock and denial often go hand in hand. Also, some may re-experience some of these stages. For example, even when acceptance occurs, the feelings of guilt and grief may reoccur.

It's Okay to Cry

Crying is truly a healing and cleansing reaction. When given traumatic or un-expected news, crying is one of the most natural reactions. It does not matter if it is good news or bad.

As a pediatric social worker in a hospital setting, I cannot count the number of times I am frantically paged in the hospital because a parent is crying. Whether the parent cries soft, silent tears or wails aloud, it is an emotionally healthy reaction.

At this time, the most I can do for them is provide emotional support and comfort by acknowledging their pain and heartache, assisting

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them with clarity of the physician's disclosure and begin providing resources that will assist them as they move forward.

What concerns me most is the parent who receives the unexpected physician's report and skips from the shock stage directly to the acceptance stage. These parents are in the social worker's office the next morning, taking notes and making detailed lists. They start calling at once for appointments and information. When it becomes difficult to speak to someone immediately, they become intensely frustrated and emotionally distressed. I have seen this happen often.

These are usually the people who need the most emotional/clinical support. They are still in shock, denial or any combination of the grief emotions. Often, it is not until they have this breakdown or breakthrough that they are able to truly grieve.

Coming to Terms with the Reality

Parents who are able to accept, experience, adjust and reinvest, are ready to deal with what God or life has dealt them. The initial grief will be losing their "dream child," but they reinvest in the child they have. For some parents, the grieving process may start again when they find that their child's outlook is poor, if not terminal.

This is why psychological intervention is important for families who have an "atypical" family member. Support groups, as well as family and individual counseling provide an outlet and comfort which lets them know they are not alone. As a helping professional, there must be value placed in religious/spiritual types of support. Spiritual counseling is often sought as an alternative or in conjunction with clinical therapy.

As parents move forward in the acceptance stage, they are able to reconstruct their expectations for their child. With guidance, parents learn how to set achievable goals for their children. Sometimes this process begins simply by encouraging the parents to get to know their children. Often parents get so caught up in the child's diagnosis, treatments

and therapies that they forget about the child as an individual. Parents have to learn their child's strengths and areas of concern. This will assist with finding and building the appropriate medical and educational teams needed.

As a social worker, my responsibility in the acceptance process is to educate parents and arm them with resources that empower. With the right information and/or psychological help, parents can move through the acceptance stage and, ultimately, be the child's greatest source of support.

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