

How Do We Feel When We Get The News About Our Child's Special Needs?

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The reactions most parents can be compared to are the stages of grief reaction.

Initially, there is shock of a sort, perhaps you felt that things were not quite right with your child, but you weren't prepared for a "diagnosis" or a "label" to go along with it.

Denial comes along, confusing the issue. It can't be. The tests are wrong. Even though the tests might be right, I can get this fixed for my child, right? My child is not disabled. He/she just can't be.

Confusion about what this all means. What can I do. What is REAL advice and not professional jargon, etc. etc. A million questions cloud your mind.

As you decide that some of this might be true, you are angered that it had to happen with your child, your family. It isn't fair! Life is hard enough with average abilities. My child will have to struggle unfairly. Who are these people to make these judgments anyway? They don't really know my child. Did I do something to cause this problem?

Acceptance that things are not perfect begins. We must focus on the positive and strive to accommodate for the child's special needs. Who can help me with these issues?

Following are some of the feelings associated with the loss of expectation:

disbelief	need for relief
oversensitivity	nervousness
fantasy about situation	depression
frustration	guilt
blame	hopelessness
anger	restlessness

How Can We Help?

- Get the facts.
- Let the parent talk about the situation.
- Explore possibilities.
- Learn about the child's special needs.
- Find support groups.
- Express feelings.
- Build self-esteem.

Understanding the Grieving Process

Grieving is the process through which an individual separates from a significant lost dream. Successful grieving cannot happen alone. It is an emotional process which occurs through acknowledging and expressing to others the feelings that accompany the loss. It is an emotional reaction which is normal and healthy and necessary for coping with a painful reality.

Emotions help us to adjust and go on with our lives, to resolve certain issues and begin preparing for the challenges ahead. Emotions do not occur in any particular sequence or

predictable stages. They vary from person to person in intensity as well as duration. Because having a child with a disability is not a common or expected event, the unexpected reactions can be both painful and frightening to parents and can serve to create feelings of isolation.

Parents are in a unique position of providing support to one another through the difficult process of growth which occurs after the birth or identification of a child with a disability.

Emotions:

- are natural and normal
- are not experienced in any predictable order
- reoccur during one's life, often triggered by developmental milestones or setbacks
- vary in intensity according to individual circumstances and experiences
- may occur unexpectedly
- are not clear cut

Examples of Emotions/Coping With Grief

Shock and Numbness

- * allows parents to hear devastating news and still function
- * is a temporary escape from reality
- * is nature's way of giving them time to withdraw and develop support systems
- * keeps them from facing the grim reality all at once

When parents are in a state of shock and numbness, they feel:

paralyzed
in a daze
devoid of sensation and emotion
temporarily anesthetized

Denial and Disbelief

- * a refusal to admit the reality of the situation
- * an instinctive protection against difficult knowledge
- * a reaction which helps parents avoid knowing the agony of pain
- * an emotion which gives parents time to get support to help deal with their loss

When parents are in a state of denial and disbelief, they:

may disregard the diagnosis or refuse to believe it block out what they are fearful of accepting
may keep looking for a doctor to tell them what they want to hear about their child
say to themselves, "this is not happening to me."

Anger and Hostility

- * a feeling of alarm caused by an awareness of a new and threatening situation
- * a feeling of rage aroused by what is considered unjust
- * motion which causes one to be critical of everything and everyone

When parents are in a state of anger and hostility, they often:

grope for answers to "why" - why me, why my child, why now?
direct it toward the medical personnel involved in giving information about their child's problem
direct it toward their child, spouse, or God
feel anger about the burden, disruption, and pain they feel have befallen them

Fear

- * a feeling of alarm caused by an anticipation or awareness
- * a state of dread or heightened concern
- * an intense reluctance to face the future
- * an intense apprehension

When parents are fearful, they:

feel they might not be strong enough to survive the crisis feel that they will never find happiness

feel that they are inadequate and unable to deal with their child's needs are anxious about the unknown

are uncomfortable with what they do not understand are worried about the future

are concerned about how brothers and sisters will be affected are anxious about society's reaction

Guilt

- * a self-centered reaction
- * an impulse to hold oneself responsible
- * a parent's feeling of having done something wrong (or having failed to take the proper action)
- * a regretful awareness

When parents feel guilty, they say:

"If only I had..."

"Why didn't I..."

"Did I do something to cause the problem?"

"Am I being punished?"

"Why me?"

Blame

- * an other-centered reaction
- * an impulse to hold others responsible
- * a parent's feeling that someone else has done something wrong (or failed to take the proper action)

When parents blame, they say:

"The doctor should have..."

"Why didn't they..."

"If only they had..."

"Why did God allow this to happen to me?"

Depression and Loneliness

- * a time of apathy, nothingness
- * a time of self-imposed exile
- * a time of robot-like existence
- * a time of physical and mental isolation

When parents are in a state of depression and loneliness, they feel:

no joy is left in life circumstances will not improve it is an effort to get through each moment no one has ever hurt as they are hurting no one understands what they are experiencing they do not want to think, plan, or deal with the situation

Acknowledgement/Understanding/Adjustment

- * a clear awareness of the nature of the situation
- * a resolution of conflicting emotions
- * a determination to move forward and to act in positive ways

When parents reach a place of understanding, they:

accept the fact that they have experienced a major loss face up to their feelings and emotions
 find courage to go through the surviving, healing and growing process
 have hope for the future

Examples of Coping Strategies

Physical Coping Strategies

cry
 laugh
 exercise
 eat as well as you can
 get sufficient rest
 take long walks
 take time for yourself
 keep daily routines as normal as possible
 let things go for awhile - be less organized and less productive
 listen to relaxing music

Cognitive Coping Strategies

get information on your child's disability talk to doctors - request information talk to a parent of a child with a similar disability read books on the subject of your child's disability ask questions -- "What does _____mean?"

Spiritual/Inspirational Coping Strategies

talk to a priest, rabbi, pastor
 read devotionals, bible, inspirational stories
 pray
 spend quiet time in a peaceful setting -- in the woods, by a lake

Psychological Coping Strategies

recognize your own feels, anxieties, fears, and desires
 understand the magnitude of what you have lost
 allow yourself to grieve fully
 do not be afraid to show emotion
 transcend your guilt
 find one person to support you and give you a sense of hope
 talk to your spouse, other children, significant others
 get professional counseling if needed
 join a parent support group
 find a reason to live - do not live in the past
 take one day at a time
 accept life the way it is
 time may soften the hurt
 realize you're not alone
 count your blessings, allow positive feelings to overtake the more negative ones
 remember the child comes first, the "special needs" come second