

Learning that your child has a disability or chronic health need often comes as a tremendous blow. Some parents describe the pain as "the feeling that I'd been hit in the stomach and couldn't breathe," "feeling like someone had torn a gaping wound in my body which hurt worse than anything I'd ever felt" or "having a black sack pulled over my head and I couldn't hear, see or think normally."

Whatever your experience, you should realize your feelings are legitimate and there are other parents who have experienced similar feelings. The feelings are likely to change often and there are things you can do to help yourself survive this emotional roller coaster.

It doesn't matter what it is called -- the grief cycle, chronic sorrow, recurring grief," -- the emotional roller coaster takes its toll.

### The moment your life changes

As a parent, the moment that someone, usually an educator or medical specialist, tells you that your child has a disability or special health need is the moment that your life changes in crucial and irrevocable ways.

The first reaction to diagnosis may be:

- this can't be happening;
- there's nothing wrong with my child;
- the doctors must have made a mistake;
- the tests were switched

**Denial** buys us time to find internal strengths and external supports -- it is a normal coping mechanism. There are parents who have suspected something isn't quite right with their child -- for those parents diagnosis is a validation of what they have feared, and they may react with relief that someone has finally listened to them. Even though these parents have suspected that something was not right, they will still go through a period of adjustment when a definite diagnosis is received.

**Anger** and **fear** frequently coincide with, or follow, denial -- many times the educator or medical personnel who gives the diagnosis bear the brunt of the anger. Fear is a mechanism the mind uses to permit a person to deal with feelings of vulnerability and loss. Anger can also be useful to allow a person to gain new perspectives and to reevaluate beliefs about justice and fairness.

Another emotion parents are likely to encounter is **guilt**. "Did I do something to cause this? Am I being punished for something I have done? Did I take care of myself when I was pregnant?" are just a few of the questions which may arise.

**Confusion** may also be experienced. You can't sleep or make decisions, and feel like you are on mental overload. Confusion may be the result of not fully understanding what is happening, of having to deal with

new terms which have never been heard before and of not being able to make sense of what is being said.

One of the most common reactions to being told that a child has a disability or serious medical condition is a sort of mental shut down -- you hear the initial news, and then don't hear anything else. Even though you may seem to be listening, the diagnosis is filling your mind and heart to the point where you are just going through the motions. You may feel like you are in a daze and can't reconnect with the world.

Other emotions you may experience are a sense of **powerlessness, disappointment** and **rejection**. As a parent, it is extremely difficult for to accept that you can't "fix" whatever is wrong, or change the fact that your child has a disability. You must also deal with the reality that you must now rely on more professionals than you ever knew could have an impact on your life -- specialists, therapists, infant stimulation providers, developmental preschool teachers, case managers, special educators -- the list seems to get longer every day.

The fact that your child isn't the "perfect" one which was anticipated can threaten egos and challenge value systems, making it difficult to accept the child just as he or she is, and perhaps even setting up feelings of rejection. It is not uncommon for parents to report that at the deepest point of depression they had feelings of wishing their child had not lived.

Once you are able to get past the denial, and deal with the other emotions, you are ready to begin **searching**. There is power in having information, and it helps relieve stress to be doing something -- finding professionals who inspire trust, learning the terminology, gaining knowledge about the diagnosis or disability, and locating programs and services -- can help you focus on the fact that there is help for your child and for you. However, some parents take searching to the extreme and go from doctor to doctor, looking for the one who will say what they want to hear -- that the disability doesn't exist or will go away.

Not all of the emotions will be experienced by all parents -- and different people will work through them in various ways and on their own time frame. Very often mom and dad will be at different stages, which can cause additional turmoil. It is crucial for parents to understand that you are not alone on this roller coaster of feelings.

It is important for you, as the parent of a child with a special need, to begin reaching out for support as early as possible. The time after a diagnosis is a time of isolation and it is extremely helpful to find support and empathy.

Often a parent with an older child with the same or a similar disability can be of a great deal of help to parents

just facing all of the searching and decisions. These "veteran" parents have been through the "mine fields" and can pass along their experiences and knowledge, as well as just being there to listen.

Although you will pass through a wide range of emotions, you will eventually come to some measure of **acceptance** and **stability**. However don't be surprised if the emotions return, especially during developmental milestones such as:

- birth or initial diagnosis
- every time you take your child for more tests
- when you see a healthy child doing something your child can't do
- entry into programs
- rejection by peers/siblings
- school entrance
- puberty
- transitions from one program to another (middle school to high school, school to work)
- the time when most young people become independent of their parents
- as you approach retirement or worry about what will happen to your child should you die
- every year at IEP time!

As you build support systems and learn where to go for answers, you will recognize and pass through the stages of grief with less stress, and have longer periods of acceptance. However, when your child has a disability or special health need, it is unrealistic to stop feeling the sadness. As parents of children with special needs, we are confronted every day with challenges and crises which don't ordinarily occur with children who do not have disabilities. It is as if the original wounds are opened over again, sometimes when least expected.

You should also recognize that others in the family will need support and encouragement also. Siblings of children with disabilities grieve, as do grandparents. Not only do grandparents grieve for their grandchild, they grieve for what you, their own child, are experiencing.

It is important for you and your family to know that you are not alone, that there are others who understand what you are going through and can offer support. Remember that the emotions you are experiencing are normal, and each step in the process brings you closer to acceptance of your child just as he or she is and not as you may have hoped or dreamed he or she would be. There is hope. The day will come when you will know that this child is more like other children than unlike them. You don't have to ride the roller coaster alone!

## Some things that help . . .

- ☞ Love your child for who he or she is -- a unique, special little person with more "alikes" than "differents";
- ☞ Talk with others -- family, friends, a spiritual or mental health counselor. Let others help carry the emotional burden and help you deal with your feelings;
- ☞ Let others help with things like laundry, cleaning, child care -- remember, just because you have a child with special needs, you don't have to be "supermom" or "superdad." You can't do it all!
- ☞ Take one day at a time -- throw out the "what ifs" and "if onlys" and concentrate on getting through today in the best way possible;
- ☞ Do not be intimidated -- this is your child and what is happening has a profound effect on your life and your child's future. Learn as much as you can about your child's diagnosis, the terminology, and various programs and services and decide what you believe is right for your child and your family;
- ☞ Don't settle only for competent medical and educational services - seek **competent and caring** services;
- ☞ Do not be afraid of your emotions -- they are not a sign of weakness, but of love for your child
- ☞ Cultivate a positive attitude -- look for the positives and celebrate them (a beautiful smile, an hour or a day without seizures, a small step forward after several steps back, etc.);
- ☞ Take care of yourself -- you can't take care of your child if you don't take care of yourself first. Get enough sleep, eat well, learn stress management techniques, find time for yourself;
- ☞ Treat yourself to something special and hang on to some of your own interests -- there is life after diagnosis and there is life beyond disability;
- ☞ Establish daily routines -- it can give a sense of consistency and normalcy to lives that have been turned upside down;
- ☞ Connect with other parents who have children with disabilities and/or join a support group -- people who have "been there" can truly understand what you are going through;
- ☞ Keep your sense of humor -- the best stress reliever is laughter.

### BIBLIOGRAPHY

"PIC'S -N-PIECES" Volume 3, issue 3, Lost Dreams  
"NICHCY News Digest" Volume III, Number 1.

## For more information about PARENTING A CHILD WITH SPECIAL NEEDS

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