

# **The Impact of Childhood Disability**

## **The Parent's Struggle**

### **By Ken Moses Ph.D**

Parents, all *parents*, attach to their children through dreams, fantasies, illusions, and projections into the future. Children are our second chance, our ultimate "life products," the reflection and extension of our very being. To know that a human life exists that grows from our genes, our bodies, that is a result of our existence, brings a measure of spirituality into the most hardened individual. Something basic to our sense of being is stirred when we witness the miracle of the continuity of life. What happens when this core experience is marred irreversibly by disability? How does a parent survive the devastation of a handicap in their child that shatters their heartfelt dream? How do they go on? How can they help their child, their other children, themselves?

As disability bluntly shatters the dreams, parents face a complicated, draining, challenging, frightening, and consuming task. They must raise the child they have, while letting go of the child they dreamed of. They must go on with their lives, cope with their child as he or she is now, let go of the lost dreams and generate new dreams. To do all this, the parent must experience the process of grieving,

Grieving is an unlearned, spontaneous, and self-sufficient process. It consists of states of feeling that provide the opportunity for self-examination, leading to both internal and external change. The grieving states that facilitate separation from a lost dream are as follows: denial, anxiety, fear, guilt, depression, and anger. The word states" is used instead of "stages," to emphasize grieving is *not* a step-by-step process that evolves through discrete stages. This depiction of what a parent goes through is a presentation of theory, not irrefutable fact. It is meant to help people find their own ways of dealing with the unspeakable. I look at it as a map, not a recipe. A recipe tells people what to do if they desire a particular result. A map on the other hand, is one person's partial impression of reality that can be used by another to help them get to where they wish to go.

Parents attach to children through core-level dreams, fantasies, illusions, and projections into the future. Disability, dashes these cherished dreams. The impairment, *not the child*, irreversibly, spoils a parent's fundamental, heart-felt yearning. Disability shatters the dreams, fantasies, illusions, and projections into the future that parents generate as pan of their struggle to accomplish basic life missions. Parents of impaired children grieve for the loss of dreams that are key to the meaning of their existence, to their sense of being. Recovering from such a loss depends on one's ability to separate from the lost dream, and to generate new, more attainable dreams.

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When theories of grieving are used as a recipe to produce acceptance, two false premises are inflicted on parents. The premise that grieving should move through a specific order is flatly inaccurate. A consistent pattern is *not* evident in people dealing with loss! Worse, when people believe that they are supposed to grieve in a certain way, they often end up thinking they are doing it wrong. Secondly, the concept of acceptance is totally unfounded. In almost twenty years of working with bereaved people, as well as dealing with my, own losses. I have never seen anyone achieve acceptance of loss, only acknowledgement.

Resisting the grieving process, they hold feelings in, blame self or others, become embittered, dependent, or even bizarre in their interactions. They can range from the selfless crusader to the deserter, from the alcoholic to the workaholic, from the outrageously high-strung to the person who barely moves or talks. However they manifest their stuckness, these are the people who have become worse, not better, in response to loss. These are the people who could not or would not experience the feelings of grieving. Many of them resisted the process because their subculture (their family, neighbors, church, schools, and friends) sent out a consistent message: the feelings of grieving are *not* acceptable! Others foundered because they were stuck emotionally before they had their impaired child. Regardless of background, people become worse if they resist experiencing and sharing the spontaneous feelings of grieving. Each feeling state, no matter how negative, serves a specific and helpful function. To separate from a lost dream, one must experience and share denial, anxiety, fear, guilt, depression and anger in whatever order or manner the feelings surface.

### **The Feeling States of Grieving**

#### **Denial**

People who deny are considered stupid, obstructionists, dull or deliberately irritating by many who have to deal with them. None of that is true. Parents of impaired children manifest denial as a normal course of trying to deal competently with loss. It is impossible to live life fully while maintaining an awareness of the awful things that can happen to people. Most people routinely shield themselves with such thoughts as "The terrible things that happen to other people can't happen to me, because..." This system works fine as long as nothing terrible happens, but when it does, no one is prepared to deal with it. This is where denial in the service of grieving comes in. Denial buys the time needed to blunt the initial impact of the shattered dream, to discover the inner strengths needed to confront what has really happened, and to find the people and resources needed to deal with a crisis for which one could not be prepared.

#### **Anxiety**

When a person loses a dream that is central to their being they are forced to make major changes within themselves and within their environment. To deal with having an impaired child, parents go through dramatic changes that affect their attitudes, priorities, values, and beliefs, as well as altering day-to-day routines. Such changes require a great deal of energy. Anxiety mobilizes the energy needed to make these changes. Further, it gives focus to that energy so that the changes can be actualized. Anxiety, is the inner source of the need to act.

Anxiety, is generally seen as hysterical, inappropriate, and unacceptable. The culture's message is clear. As a rule we advise anxious people to "calm down," to take medication, or to use alcohol as a "solution" for the "problem" of anxiety. These *unsolutions* keep the parent from changing and often make things worse for all concerned. Realities must be faced, stressful as they might be. It does not take long for most parents to become aware that they, not some professional, are their child's medical, educational, and therapy managers, even though they may have minimal knowledge of these areas. That alone should drive home the urgent need for energies to be mobilized and focused by the crucial feeling of anxiety.

### **Fear**

As anxiety mobilizes people to deal with change, fear is a warning that alerts the person to the seriousness of the internal changes that are demanded. One's sense of balance and order are dramatically challenged when one confronts a meaningful loss. The parents experience the terror of knowing that they will be required to change on a fundamental level, against their will, with full understanding that the process of internal change is very difficult.

Significant losses produce a profound sense of abandonment and vulnerability. We have a number of sayings to cope with this level of fear, e.g., "It is far better to have loved and lost, than to have never loved at all." Each person must find their own words to confront the sense of abandonment and vulnerability generated by a significant loss. Most parents experience the *fear* of vulnerability about having more children after they have had an impaired child, or about "over-protectionism," the gut wrenching fear of permitting their impaired child to do anything that feels risky. Given the ways that this part of grieving is manifest, it should not be difficult to see that fear is the medium that encourages the struggle to reattach, to love again in the face of a loss.

### **Guilt**

Parents of impaired children manifest guilt through the normal course of grieving and are often criticized for doing so. Guilt is a feeling state that has become so identified with being neurotic that people feel guilty about feeling guilty. Since sharing such feelings often evokes negative judgments, it can be difficult for a sophisticated parent to talk about guilt freely. On the surface, guilt-ridden people may appear not only neurotic, but superstitious, ignorant and primitive. They are often viewed as unpleasant, uncomfortable people to be with and therefore are dismissed or treated harshly by friends, family, and professionals.

Generally, parents of impaired children express guilt in one of three ways. One way is by telling a story that explains how they are responsible for their child's handicap. Their story is often accurate and, on the whole, persuasive. The current emphasis on the prevention of birth defects has brought many parents to feel that they caused their child's impairment. The issue is not the logic, but the feeling of guilt. Another way that guilt is manifested is in the conviction that the child's impairment is punished for a past inappropriate thought, feeling, or action. One of the more common "guilt thoughts" is regretting the pregnancy sometime during gestation. When something goes wrong after that thought occurs, "it's all my fault" becomes a natural outcome. Lastly, guilt can be expressed through the parent's belief that good things happen to good people, and bad things happen to bad people. Because parents have an impaired child, they must be bad people. Because they have an impaired child, they must be bad people and consequently feel

shame and guilt. How can such painful explanations of tragedy be useful to bereaved individuals? Simply by *being* explanations. Guilt "explains" the unexplainable. Human beings begin to question the "why" of things from very early on in their lives. What are the rules that govern the way of things: cause and effect as well as right and wrong? A most important "why" concerns how one's "right" or "wrong" actions effect one's life. What difference does it make that a person is moral, ethical, legal, caring, ambitious? How is it that one does or does not influence the events of one's life? Some of us found early and easy answers to these questions and have not considered them since. After a loss, such questions cannot be answered in an ordinary fashion. Rather, they must be addressed through the kind of grief-related struggles addressed here. When people confront a loss, the beliefs they held regarding cause and effect, right and wrong, and their impact upon life are deeply shaken. The order of things is totally upset when an innocent child suffers. The parent experiences deep pain, pain that can be used to reorder the rightness of the world. Guilt is the feeling state that facilitates this struggle to reorder. Basically the guilt-ridden person is saying that they are accepting responsibility for everything. It feels better to do that than to believe that they have no influence on anything! Guilt, in this sense helps one to redefine the issue of cause and responsibility in the light of loss.

### **Depression**

A common response to loss often is characterized by profound and painful sobbing. Parents report that at times it feels as though the tears will never stop. There is a rest, but then for no apparent reason, waves of despair and anguish wash over the parent once more. Between the tears, one can sit alone, staring silently. Those periods of silence can last well beyond the periods of tears. The thoughts of depression take over, thoughts like: "What's the use of trying, it's all over." or "Nothing I do matters, because nothing will change what has happened to my child!" Depression is subtly rejected and judged as pathological by much of our culture. When people display such feelings, they are often told to "cheer up", given medication, or offered distractions. Such responses are inappropriate, for depression is part of normal, necessary, and growthful grieving. It attends to another aspect of a basic human struggle that loss stirs.

As we mature, we develop and modify our definitions of the following words: competence, capability, value and potency. They are words of profound personal significance. They are the criteria that people use to decide if they are OK or not. What criteria does a person have to meet to feel like a competent parent, a capable worker, a valued friend, or a strong person? Each person determines these standards privately, even secretly, when parents are confronted with an impaired child, whatever definitions they held for competency, capability, value, and potency usually no longer apply. How does a mother feel competent when she has a retarded daughter? She can't use the measures of her peers, like having a daughter graduate from college, or become homecoming queen. What is the worth of a father who cannot "fix" what is broken in his impaired son? Out of this struggle of defining one's worth come the frightening feelings of helplessness, hopelessness, and haplessness. Faced with loss, a parent feels unable to act effectively (helpless), unable to imagine that things will ever get better (hopelessness), and unable to believe that their lives are touched by good luck (hapless). Such feelings are terrifying for both the parents and those around them. For that reason, it is hard to see that depression is a normal and *necessary* part of the grieving process. Depression is the medium that helps parents come to new definitions of what it takes to be a competent, capable, valuable and strong people, even though their child has impairments that they cannot cure.

## Anger

Anger, for many people, is the most disconcerting of the feeling states. It too is a natural and necessary part of the grieving process. Parents feel anger at the harm done to their child and the shattering of their dreams. When one encounters a significant loss, it is likely that one's internal sense of justice is severely challenged. To continue to trust in the world, one must have a sense of justice that confirms an orderliness and fairness to the way the world works.

A parent can righteously demand to know why he or she has an impaired child: "Why me, why not you!" Implicit in the question is the notion that there must be good reason that such a thing happens to one parent and not to another. A parent's concepts of justice, like value and worth, is another unique product of that individual's thinking and development. When confronted with the traumatic loss of a dream, that internal sense of justice is violated. Crying out in the face of injustice, the parent develops new ways to look at justice in the world. "What, after all, is fair, if this can happen?" Anger is the medium through which a parent redefines fairness and justice. It integrates new beliefs within the deepest emotional levels of the grieving parent.

Unfortunately, anger is an emotion that is actively rejected by the culture at large and by people closest to the parent. The angry parent experiences rejection by others, confusion about *feeling* anger and *acting out* the feeling, the feeling of being out of control. All of this makes it very difficult for this important feeling to run its course.

Anger also poses other dilemmas. Unlike the other feeling states of grieving, anger is directed toward someone or something. Who (or what) is the object of parental anger? This question deeply distresses most parents, because the honest answer is often so troubling that many people avoid asking themselves the question. The unacceptable answer, of course, is that the impaired child is the object of anger. After all, who has entered this parent's life, disrupted it, caused immeasurable pain, and drained the parent's time, energy, and money.