

## **The Cycle of Love and Grief in Parents of Children with Special Needs**

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If there is anything that a parent of a child with special needs knows, it is that love is costly. Love requires work, work that is physical, emotional, and relational. Love requires effort, focus, leaving one's comfort zone, and learning lessons one never thought were on life's curriculum.

There are those parents, however, who would be loath to describe love in this way. These parents might acknowledge that, yes, it is hard work to raise their child, and that their child does need much more time, attention, and energy than children who are typically developing. But what they, as parents who love their children give, they give freely, and what they receive is greater than what they give.

This is not what they would have said on the day of diagnosis. It is a hard-won insight, and one reached after investing in their child's well-being and development for a long time. It is an insight achieved after a journey of both deep grief and intense joy, of cycles of dread and relief, of falling into the depths of despair, but reawakening to hope, all moved along by an unwavering commitment fed by the deep wells of parental love.

Dr. Ken Moses has spent decades studying the process of grief in parents of children with special needs. He asserts that grieving is an unlearned, spontaneous, and self-sufficient process.<sup>1</sup> Though parents may not feel healthy or be aware of

growth as they grieve, the journey they are on provides them with the protection, energy, focus, boundaries, bonding, and reflection that they need to make sense of the loss of dreams and expectations that they are experiencing, and to shape their efforts to do whatever is in their power to help their child develop to his or her fullest potential. Dr. Moses asserts that grieving is experienced as states, not stages. There is no predictable order to the grieving process but there are certain grieving states which most parents will experience to some degree or other.

The most universal grieving states experienced by parents are denial, anxiety, fear, anger, guilt, and depression. Parents also describe sadness (as opposed to depression, which often includes despair), envy, confusion, and loneliness. Each of these grieving states provides important and necessary functions that are difficult to obtain outside of the grieving journey. The difficult emotions experienced within the context of grief are considered healthy, rather than pathological, and when well-invested, can supply a great source of fuel towards the goal of a child's successful development. They may also be the impetus behind significant social and policy changes, as parents become pioneers and leaders beyond the boundaries of their own families.

It must be acknowledged that the diagnosis, while experienced as a severe blow for most, actually can provide significant relief for others who have been searching for an answer for an extended period of time. Some parents know their child is not developing like other children, and they assiduously seek professional corroboration and support, which may not be forthcoming. After a great deal of effort and waiting, parents finally find the professional who gives them the answers they have been looking for. Though there may be grief in finally knowing, the relief that it is not something worse, that their child's problem has a name, a protocol, and something that can be done, is greater than the heartache of a confirmed disability.

### **Denial**

Denial is a life-preserving instinct that provides protection against unbearable truth until one can gather the resources necessary to process it and respond appropriately. Without some measure of denial, most people would not be able to get up in the morning. We all know at some level that disaster can strike when we least expect it, but this doesn't keep us from leaving our homes, getting into our automobiles, and venturing out in traffic. When disaster does strike in the form of a serious, life-changing diagnosis, denial of feelings in the form of shock or numbness can help parents continue functioning and follow through on the necessary steps to get the intervention the child needs. The day of diagnosis may be accompanied by intense shock and a feeling of unreality. Many describe

receiving the news as a feeling akin to being hit by a train. The jolt is so overwhelming that initially true pain only comes in waves and is relieved for periods of time by detached numbness, a sense that "this can't be happening; the professional must be wrong."

Denial can afford balance within a family. While one parent is grieving consciously and intensely, the other may automatically hunker down, put on a stable and stoic front, and thus provide ballast to a ship that is being tossed by the emotional storm occasioned by the child's disability. Often, though not always, it is the man that makes the unconscious choice to embrace the denial of feelings. Or, he may do it only in the presence of his wife, whom, he fears, will become even more unbalanced if she sees him fall apart.

When couples understand intuitively that their partners are balancing out what is happening emotionally, this arrangement can work very well. However, when emotional denial goes on rigidly over a long period of time it can become troublesome to an intimate relationship such as marriage, as well as a parent-professional partnership. Partners can make inaccurate assumptions about the other. Wives may assume that their husbands just don't care very much about their child's problem, may feel that the burden has been unfairly placed on their shoulders, and may develop loneliness and resentment. Husbands may view their wives as needy and unstable, even while admiring their strength and ability to "get things done" and

take care of their child's special needs. Professionals who do not understand and embrace the functions of grief may become impatient with a parent's pace in taking certain necessary steps towards their child's habilitation.

Without a necessary degree of denial, a parent would be incapable of going on and taking the recommended steps to intervene on their child's behalf. As Dr. Moses explains, denial "buys time to blunt the initial impact of the shattered dreams, to discover the inner strengths needed to confront what has happened, and to find the people and resources needed to deal with a crisis for which one could not be prepared."

### **Anxiety**

Anxiety is occasioned by entering the unknown world of one's child's disability. There is so much to learn, so many changes to make (many of which are costly and difficult) and so many decisions to come to. Parents can be flooded with information, contradictory advice and opinions, and obstacles in finding services. Their world has been turned upside down, and they feel unequal to the task of putting it to rights. Anxiety can affect sleeping and eating patterns, and can cause constant thoughts and worries to overwhelm the sufferer.

"I used to be a great sleeper," says Jonathan. "But now I wake up every night and worry about whether I'll be able to persuade the insurance company to pay for the surgery that Connor needs. They claim that it's experimental and that they are not obligated to pay for it."

And yet, anxiety provides energy. When parents have a clear set of instructions and a direction to head in, their anxiety provides both fuel and focus to achieve what needs to be done. And if the direction is not yet clear to them, anxiety still propels them forward, providing motivation to search for answers until some strategy presents itself as the best course of action.

### **Fear**

Fear is anxiety on steroids. It is the jolt in the middle of the night that wakes parents and propels them from their beds to their child's room to check that they are breathing. Parents who are facing their child's disability can feel vulnerable in the face of the unknown. In the almond-shaped amygdala of the human brain, fear is an outpouring of stress hormones that surge through the nervous system, prompting an instinct to fight, flight, or freeze.

Fear is, in the words of Dr. Moses, "a warning that alerts the person to the seriousness of the ... changes that are demanded." How does fear help parents? Fear that is consciously recognized intensifies the bond between parent and child, cementing the commitment to protect and do whatever is within the parent's reach to provide the child with what is needed for his short and long-term success.

### **Guilt**

Guilt is a natural state for any parent, but it is intensified exponentially when a child has a disability. Guilt begins with the questions about the source of the child's disability.

Parents will wonder repeatedly what they may have done to cause the disability during pregnancy. They do a searching inventory of all they ate or drank, activities that they engaged in, and anything that the pre-born child may have been exposed to. They review the birth process looking for errors. When this search proves fruitless, they begin thinking about whether something they thought, felt or did made them unworthy, and whether this is Life's or God's way of punishing them. It may be intolerable for a long time not to have an explanation for their child's disability. It is preferable to feel that they somehow caused it then to think that such terrible things happen randomly, and there is no control in their lives or the universe. Aside from questions of origin, parents feel guilty if they don't spend every minute of every day helping their child in some way.

"The other night I went out with my girlfriends for the first time since Isabella was born," says Megan. "I felt so guilty about leaving Isabella that I just thought about her the whole night and didn't enjoy myself that much. I just love her so much and it feels wrong to leave her just to have fun. I'm going to have to work on that."

Parents also feel guilty if they get angry at the child or at God for making their lives so challenging. They feel guilty if they snap at their children or their spouse in a moment of fatigue or overwhelm.

Guilt can compel a parent to try their hardest to help their children succeed. But it is also a way to figure out something that many people know

intellectually but have not yet embraced emotionally: "The rain falls on the just and the unjust alike" (Matthew 5:45, the Bible). A related truth is that many of life's blessings are given freely, not earned, and many of life's difficulties are not deserved either. And that there is little anyone can do to alter this reality. "Why me?" becomes "Why not me?" as the question to consider when seeking a reason for one's child's disability. And since there is no logical reason to be found, parents decide to make the best of it, and just take care of their children, as well as themselves.

### **Anger**

Many people find anger troublesome. It is a very "contagious" emotion, one that can easily elicit reciprocal anger, or fear, anxiety, and intimidation in those who witness it in another. And yet anger is a natural part of the grieving process, one that is prompted by a host of circumstances that appear unfair, unjust, and illogical. The "why me" question is often accompanied not only by guilt but also by anger as parents realize that there was nothing they did, felt, or said to deserve such a fate. Throughout the journey of grief, repeated events can prompt anger in parents: professional incompetence or apparent indifference, insensitivity or cruelty on the part of loved ones and strangers, failure to achieve goals that one has set out to accomplish due to obstacles placed by systems or individuals, or by the child's lack of progress despite one's best efforts. The bottom line is: the child did nothing to bring his condition upon himself, and it isn't fair that the parents must radically alter their lifestyle in order to solve innumerable

problems and challenges that present themselves on a daily basis. It isn't fair to have to bury shattered dreams. Life is radically less fair than the parents had expected it to be.

Nonetheless, without anger, the world would be unlikely to change in any significant way. Parental anger has been the source of, and provided the fuel for, vast changes in policies, educational and medical practices, access, and even technological changes that greatly enhance the lives and function of children and adults with disabilities. Anger can generate courage heretofore unknown to the parent whose temperament is sensitive, accommodating and loath to causing ripples or discomfort in others.

A mother's trip to a state capital to meet with legislators resulted in medical policy change that provided authorization for the state children's insurance system to cover the prosthetic device that her son needed. Not only did her son receive the needed device, but thousands of children that followed him did as well. That would never have taken place without this mother's passion fueled by anger. Anger well-managed can open doors, whereas anger that is poorly timed, explosive, or misplaced can cause damage that is difficult to repair. The reflective process helps parents to understand their anger, consider how to let it help them, and then invest it wisely with satisfying results.

### **Depression**

Many people wonder what depression could possibly contribute to a grieving

parent. How could lack of energy, motivation, and enjoyment, and a bleak view of life help move parents forward and provide them with the tools they need to help their children? Kevin, who was a competitive distance runner and whose son was born with multiple medical needs says, "I don't know what's wrong with me. I don't feel like doing anything fun anymore. Not even running. And I'm really getting out of shape."

Though there are certainly some risks associated with depression, it can also be seen as a forced period of rest. The overabundance of stress hormones that accompany so many grief states creates a series of events that result in the reduction of serotonin, a hormone essential to feelings of well-being and energy.<sup>2</sup> Thus, the brain needs a time to recover and recuperate and return to a more balanced state. The body needs a chance to rest. The parent needs some time off from the roller coaster that they have been riding since the diagnosis.

Depression can be accompanied by pessimistic thoughts and projections into the future. These thoughts are usually inaccurate, because many depressed people, especially when young, assume that life will always be this difficult, and that they will never feel joy again. They may long for an earlier, simpler stage of life that wasn't associated with so much difficulty and pain.

There can be some honest sorting out that happens during a period of depression, however. Depression can be a warning that parents are running on empty, that they have spent their

reserves, and it is time for change. Parents may realize that they cannot keep up the frenzied pace they were experiencing earlier. They may understand that they need to put the brakes on their lives and take steps to bring balance and sustainability back into their lifestyles. This is an opportunity to decide what is most important; it is a chance to prioritize. Depression may force a parent to make the difficult decision to leave work and devote herself full time to caring for her child, even though it may imply a significant change in income and lifestyle. Or, a parent may decide that this is the time to leave a drug-addicted or abusive spouse so that the child can be cared for in a more stable environment.

One of depression's greatest gifts is a warning that a parent *must* begin to care for herself before she suffers more serious consequences than feeling blue and lethargic. She may come to the conclusion that she cannot continue being all things to all people, and that she must set boundaries in some of her more needy relationships. She may stop doing volunteer work at her church or listening to endless phone calls from a friend that is going through a divorce. Or, instead of taking her child to daily therapy each afternoon, she will go on a brisk walk at least once a week, pushing the child in a stroller, and get the exercise she desperately needs.

### **Sadness**

Though sadness may be felt during a period of depression, sadness often stands alone, and may not be part of a depressive state. Sadness is a sense of

being engulfed in waves of regret, sorrow, weakness, and need. Sadness can be experienced briefly, followed by relief, or can last for longer periods of time and evolve into depression.

Reflections similar to those that take place during depression can happen with sadness. Most people who are able to cry when they are sad and receive empathic support from another person when crying often feel better after crying; shared pain can diminish sadness and create bonding and trust. About a 10<sup>th</sup> of people who cry, however, report feeling worse after a crying episode, particularly when the crying is associated with embarrassment, shame, or scorn from another person.<sup>3</sup>

"Sometimes I'm a little embarrassed about crying in support group," Alice says. "But I always feel better afterwards because everybody is so nice to me there and everyone 'gets it.'"

When sadness is accompanied by crying, parents can experience certain important benefits. Crying can be a cause of arousal, with increased heart rate and sweating. However, research also shows that crying has preventive and restorative benefits for physical, as well as emotional, health.<sup>3</sup> Stress hormones such as cortisol are released in tears, and the subsequent calming effect seems to last longer than the arousal. A chronic overabundance of stress hormones in one's body can damage virtually all anatomical systems. Maybe that is why a Jewish proverb says, "What soap is for the body, tears are for the soul."

## **Envy**

Parents report feelings of envy sometimes. They may see a group of children playing in the park or at a family reunion and experience feelings of intense longing for their own children. The longing relates to wishing that their children didn't have to try so hard to be included or to develop skills that appear to come naturally to other children. Envy may be accompanied by anger and resentment, or by sadness.

Sally, whose toddler has Down's Syndrome, shares, "Seeing my nephew, who is a month younger than Sammy, running around, while Sammy has not yet taken his first steps, was so hard. I felt jealous of my nephew and also of my sister. Their lives seem so uncomplicated. I went home from that party feeling sad and wondering whether Sammy would ever be able to run like that."

Like fear, envy can promote a need to draw close to one's child, to intensify bonding, to try even harder to help one's child succeed. When the child does show signs of success, parents get to feel envy's flip side: pride. The pride of a parent with a child with special needs is often associated with elation, headiness, and feelings of being on cloud nine.

## **Loneliness**

In support group at John Tracy Clinic, parents often tell stories of thinking that they were the only people in the world with deaf children. They experienced deep loneliness and disorientation with the diagnosis. Where they once felt that groups with whom they associated in the

community (church groups, PTA, babysitting coops, etc.) were a source of belonging, identification, and encouragement, they often find themselves drifting away from these groups. They report that the issues that the other parents in the group are concerned about now seem trivial and unimportant in comparison with the overwhelming nature of the challenges they are currently facing.

When the two members of a couple are grieving very differently, and those differences seem to be dividing them, a parent can feel quite lonely even within the marriage. It seems that their partner is not as invested in the well-being of the child as they are, that they don't feel the pain as intensely, that they are avoiding being involved, or that they are "checking out" and leaving the heavy lifting to them. Parents who are less involved with their children's treatment and are primary wage-earners also report feeling left out of the parent-child relationship, feeling less important in the family, and yearning for the closeness to their partner that they once enjoyed.

Loneliness is a great source of motivation to seek or create a community of support. When parents find other parents who have children with the same or similar disabilities as those of their children, new bonds are formed, loneliness is diminished, and the new community meets their needs for affiliation, mentoring, inspiration, resources, emotional support, and practical answers to the challenges of daily life with their child with special needs.

Marissa found herself drifting away from her husband, Mike, who was working long hours while she transported their toddler, Julie, from appointment to appointment and struggled to learn new skills and information. She didn't know whether the marriage would survive the increasing estrangement that they were developing.

"Sometimes I wonder whether Mike loves Julie even half as much as I do," Marissa says. "I know he loves her, but he just doesn't seem that interested in helping her learn."

After she found a support group for parents with children with disabilities, she persuaded her husband to attend with her. As they shared their stories with others, they made friends with another couple, Kimberly and Daniel, who had more experience than they did. In the process of cultivating this friendship, Mike began observing how Daniel interacted with his son and seemed confident and knowledgeable about his son's needs. Daniel provided inspiration and a model to Mike of ways that he could be involved with Julie. The friendship with Kimberly and Daniel not only reduced Marissa and Mike's sense of isolation and loneliness, but also drew them closer together as Mike began sharing more time and activities with his family.

### **Confusion**

Parents often receive contradictory advice from apparently credible sources. This complicates the decision-making process for them. They feel torn about who they should

trust, and what advice to follow. Confusion about diagnostic procedures, treatment and rehabilitation options, and their subsequent prognosis can create hours and days of worry.

"My deaf and hard of hearing teacher told me that cochlear implants never work," says Catherine, whose son has a profound hearing loss, "and that if I give him the implants, I'll be denying his deafness and taking away his Deaf Cultural membership. But my speech and language therapist says that they are the best thing since sliced bread. And the ENT also recommends them. They are all experienced professionals. I have no idea who to believe."

Confusion is a great motivator to search for more information, connect with role models, and find other families who are dealing with similar challenges. Like loneliness, confusion drives parents to seek community. And a supportive community helps parents to deepen their involvement with their child's habilitation, find answers that they are looking for, and diminish the anguish that accompanies the grieving process.

### **The Story of Catherine and David**

Catherine and David were a young couple whose diagnosis of their son Matthew's severe-to-profound sensorineural hearing loss threw their lives into a tailspin. They realized that at the age of two years, Matthew was behind the learning curve and they felt they only had a brief period of time to catch up.



Catherine made the difficult decision to quit her career, at least temporarily, and become a full-time mother, caregiver, and advocate for Matthew. While she sought other parents, wept openly, woke frequently at night with feelings of fear, dread, and guilt, and became increasingly exhausted in her intense efforts to “make up for lost time,”

David was the picture of calm. She never saw him shed a tear after the day of diagnosis, and he came home from work every night ready to embrace her, ask for an update on the day’s events, and listen to her share the many highs and lows she experienced with Matthew, the encounters with professional, and other parents and children that she was meeting. Neither David nor Catherine experienced denial of facts, but David enjoyed long stretches of denial of feelings that provided him with the ability to focus at his work as an electrician, make good decisions, and achieve a measure of satisfaction from his career.

Catherine, meanwhile, rarely experienced significant respite from grief during that first year following diagnosis. Though Catherine appreciated David’s interest in keeping updated on Matthew’s life, his willingness to shoulder the bread-winning function single-handedly, and his ability to remain unruffled in the face of obstacles or bad news, she noticed several things that troubled her. He seemed to be spending increasingly longer hours at work. He was not home for dinner consistently. She never saw him flinch or cry. She wondered why she was throwing

herself into helping Matthew at a frantic pace and he wasn’t, why she cried almost daily, and he never did. She wondered whether he was trying to escape the drama of her life with her deaf son by avoiding them, and whether he really even cared.

Meanwhile, David kept his sorrow and worry tamped down. He threw himself into his work, concerned that if he didn’t provide stellar service, he would be laid off like so many other employees of his large construction company. However, on several occasions on his way home at the end of the day, he stopped at a park to watch the sunset and let his feelings overcome him. He wept long and hard, wondering whether he was going to be man enough to shoulder the burden of supporting his family on his own. He winced as he remembered Catherine telling him that he was “doing it wrong” when he tried to put Matthew’s hearing aids on him. He wondered what he would find when he arrived at home. David knew that if Catherine had had a bad day, he would need to be extra calm in order to comfort her. When he had finished crying and reflecting, David went into the public restroom and washed his face. He looked carefully at his eyes to see whether there were any traces of swelling or redness. If there were, he would wait a little longer, walk around for a while to get some fresh air, and then proceed home to face Catherine and Matthew. He never knew whether they would be laughing and playing, or whether Catherine would be tense or weepy, or behave as if she resented him. Regardless of what he might find, he wanted to be prepared to show his

best face to his family, to appear strong and competent.

Over time David learned how to talk to his son. He sang to Matthew as he changed his diapers and put him to bed. He learned about the technology available to help Matthew have access to sound. David researched different brands and types of cochlear implants, made a point of talking to the audiologist and surgeon about the features of each one, and together, he and Catherine made their choice.

David accompanied Catherine and Matthew to the hospital and waited breathlessly for the cochlear implant surgery to be finished, hoping for good news from the surgeon. He held Catherine while she cried, reminded her to take deep breaths, and went to bring her coffee, as neither one of them had slept much the night before. Catherine felt reassured by David's presence in the midst of the worst tension and fear she had ever experienced. She appreciated David's affection and the way he held her hand and asked her if she was OK. David felt calmed by the care giving role he assumed the day of the surgery. His focus on Catherine kept his own dread in check. They both experienced intense relief when the surgeon appeared and let them know that all went and that they could see their son.

With access to good services and parents who were knowledgeable and involved, Matthew flourished and rapidly responded to the sound provided by his cochlear implants. Within two years after diagnosis, Matthew, now four years old, had

made three years worth of progress. His parents were relieved and proud, but they knew that there was still much work to be done. Catherine worked as hard as she could to continue helping Matthew, but she rarely cried anymore. She was busy talking with "new mothers" at Matthew speech and language center. She offered her phone number to anyone who needed information and mentoring. At this stage, she had few "bad days," though there was always the potential for an unforeseen event, such as an insensitive comment at a family reunion, to trigger a brief wave of anger or sadness. Catherine had taken time to realize that she felt quite confident in her skills and that she had a positive view of Matthew's future. She even began to feel proud that she had proven that she was strong in the face of adversity, stronger than she had previously imagined she could be.

About this time, something peculiar happened. David saw a young man in a wheelchair make his way across a park. The young man was maneuvering the wheelchair quickly along a path in the direction of a family who was carrying some coolers and baskets, the makings of a picnic. None of the family looked back to see how the man was doing, as they walked ahead, chatting together. Something about the way the young man was excluded from the family's interactions triggered a wave of intense sadness in David. He was struck by the permanent nature of this young man's disability, and his poignant efforts to be part of a group that was ignoring him. David began crying uncontrollably. He hurried to his car and sat inside as wave after

wave of unbearable sadness overcame him. He had no rational thoughts but saw visions of his beautiful Matthew as a young man surrounded by friends, all of whom were laughing and joking, and Matthew was the only one wearing two prominent cochlear implants.

This incident was the beginning of a long and deep depression for David. The depression seemed bewildering and irrational to him. Matthew was clearly showing evidence of success. He was a boy who was going places. None of that mattered. The grief work that David had postponed for two years for the sake of his family had caught up with him, and now was manifesting as episodes of weeping, the desire to be alone, embarrassment at his feelings of weakness, and continuous lethargy and fatigue. After several months of struggling, David was wise to seek professional help. He went to counseling and obtained medications from a psychiatrist. He accepted some help from another father at the speech and language center, but preferred not to discuss his depression openly with other parents. Even though Catherine was initially bewildered by David's outward manifestations of grief, she welcomed them with relief. Finally she knew that David really, truly cared about Matthew, and that she was not alone. And she empathized with his depression and sadness, having experienced both at an earlier stage. She was happy to bring David a cup of tea on his bad days, and allowed for some isolation now and then. She insisted that the two of them begin going out alone on the weekends, even though it required so much work and

expense to pick up a sitter and pay her for her services.

David's depression turned into a period of bonding for the couple. He accepted the help of the counselor with whom he shared his feelings of fear and weakness. Experiencing the non-judgmental listening of another helped alleviate some of David's despair, and over time he was able to function with the energy and determination that he once did. As Matthew grew up, David became his soccer coach, and they spent several hours a week in training and games. This "guy" activity freed up some time for Catherine to begin taking care of herself after several years of neglect. She joined a gym and exercised whenever the guys had soccer practice. On game days, the family enjoyed their time together and often had a meal with other team families after the game.

Though David and Catherine experienced their grief very differently, and on separate time lines, they were able to tolerate and complement the other's grieving needs and style. Catherine's propensity for anxiety moved her forward initially, and David's longer period in the state of denial provided some ballast and calm during a stormy period in the family's life. Even though their differences were bewildering at times, and difficult to accept, they allowed the other the space needed to do the grief work at their own pace, and in their own way. In their own ways, they provided comfort and encouragement to the other, sometimes openly and consciously, and at other times

without even realizing it. Though Catherine had had several years of intense grief, she was investing her pain wisely and using it to propel her in the direction of Matthew's needs. David saw her work for and with their son and he knew without a doubt that Matthew was in capable hands. Though David did not admit to experiencing the kind of pain that Catherine showed for several years, she was greatly relieved that he was willing to allow her to be a full time mother and to work harder to make ends meet on his own. She knew that if she had to work full time while she felt like a "basket case" she would not have been able to cope adequately with the combined demands of work and Matthew's needs. On some level she realized that David had to hold it together to continue functioning as a professional, even though she sometimes misconstrued this stoicism as not feeling or caring what was happening with their son. When David pulled out of his period of emotional denial and finally "fell apart," Catherine not only understood but felt accompanied on her journey, even though she'd moved on and found herself in a less painful place.

### **Grief is different for everyone**

Grief is a unique process for each parent that undertakes this journey. As resources, tools, and empathic support are made available to grieving parents who are searching for answers, motivated by deep love and the parent-child bond, they choose to act in ways that are helpful and constructive.

Two common characteristics of parents that successfully invest their

grief toward positive outcomes are courage and perseverance. Doing things that they find challenging by attempting frequently builds self-confidence and decreases anxiety. The "courage muscle" gets stronger with practice. Perseverance is manifest in those who don't let temporary setbacks or obstacles discourage them from trying again, perhaps tweaking their attempts toward greater success.

Whether a parent suffers deeply or moves along more gently, the grieving states, which are born of the love of a parent for a child, can be powerful sources of motivation, focus, energy, and meaning that benefit the child with the disability, and, ultimately, all persons with disabilities, their families, and society.

1 Moses, Ken: "The Impact of Childhood Disability: The Parent's Struggle," *Ways Magazine*, Spring, 1987

2 Macken, Paul and Young, Allen, "The Role of Cortisol and Depression: Exploring New Opportunities for Treatment," *Psychiatric Times*, May, 2004.

3 Rottenberg, Bylsma, and Vingerhoets, Association for Psychological Science (2008, December 19). "Cry Me A River: The Psychology Of Crying." *ScienceDaily*.

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