

Grief and Lost Dreams

Grieving touches the lives of parents and other loved ones of children with disabilities. People experience grief in their own unique way. Each may follow very different paths as they deal with their own grief. For a husband and wife, or long-time partners, the paths can vary greatly and create their own unique set of challenges.

Siblings are also impacted by grief. Children often do not demonstrate their grief the same way adults do. A child or young adult's attention span is not as long as an adult's and just because they may go out and play does not mean they are not grieving. Remember, 'children love, therefore they grieve'.

A new reality often comes quickly and abruptly to parents of children with a disability. Although it is natural if at first the mind can't shift immediately, it is important at some point to move forward to acceptance and understanding. Parents who don't move ahead often become stuck in anger, denial, despair or high anxiety levels.

There are no set 'stages' of grief, specific 'cycles' to follow and no right or wrong way. Being the parent of a child with a disability can be an emotional roller coaster. There are some typical emotions and feelings associated with grief. A parent may or may not go through these and may feel them at any time. Some parents skip these emotions, some feel more than one at a time. Some typical emotions are:

Denial—Basic disbelief about a situation that exists

Accompanying feelings or actions may be:

- *'Someone has made a mistake'*
- *'This can't be happening to us'*
- *'At some point I will wake up and this will all be over'*
- *'If I acknowledge it or say it out loud that means it's real'*

Denial has some benefits: It can keep parents from feeling overwhelmed or protect a person until they can tap their own emotions, strengths and other support systems. It is also a sign of the beginning of acceptance of a situation. If there was not a situation to deny a parent wouldn't be in denial.



Despair—Being without any hope

Accompanying feelings or actions may be:

- Mourning as if there's been a death
- The aching sorrow or sadness that comes with loss
- Disappointment that things are not turning out as hoped or dreamed
- Self-pity—'Why me? Why my child?'
- Fear or anger turned inward
- Not participating or responding to what's going on
- Building a cocoon around myself

Every one who is dealing with despair is dealing with depression at some level. It is a part of grieving. When despair becomes all-consuming and paralyzing, it is appropriate and necessary to seek professional help.

Guilt—Feeling of having done something wrong that caused the situation

Accompany feelings and actions may be:

- Admonishing myself over what I may have done
- Questioning if there is something I could have done differently to avoid this
- Feeling deserving of blame for the situation
- Believing it is punishment for some act

Feelings of guilt and self doubt are normal for parents of children with disabilities. A challenge exists, however, if guilt becomes the only focus and self-blame becomes overwhelming.

Blame—To put the responsibility on someone or something else for causing the situation

Accompanying feelings and actions may be:

- 'This is not my fault'
- 'It must be from their side of the family'
- Blaming the messenger - doctor, therapist, family member or friend
- Intense desire to find out who or what caused this situation



Anger—A hostile or inflamed feeling

Accompanying feelings and actions may be:

- Strong feelings of resentment toward others who don't have to experience what I do
- Demonstrating aggression through verbal and non-verbal expressions
- Sense of frustration over such things as lack of action, other's lack of understanding
- Wanting to lash out and hurt others, so they feel the pain and loss
- Outbursts over what I perceive as injustices
- The word 'fair' is no longer in my dictionary

Anxiety and Fear—Being uneasy or worried

Accompanying feelings and actions:

- Uncertainty and concern about what the future may hold for my child
- Uncertainty and concern about how this child with a disability will change our life and family
- Tension in my mind and body
- Frenetic thoughts about what this may mean
- Constant movement to keep the worry at bay
- Kicking into 'high gear' and becoming super efficient

Acceptance and Adjustment are a part of grief. **Acceptance** is the realization and willingness to believe that something is true or a fact, and results in coming to terms with it. Acceptance can cause mixed emotions such as: resolution, sadness or relief. **Adjustment** means adapting to new circumstances, environments or conditions and often follows acceptance. Adjustment typically represents moving forward, getting on with what needs to be done.

Grief is a healing process, which never completely ends for parents of a child with a disability. Grief is normal and healthy and not to be avoided. It is important not to run from, deny or intellectualize the feelings. One thing is certain—we need an outlet for our emotions. The goal is to **cope** with the disability.



Lost Dreams

Lost dreams and the building and creating of new dreams are an integral part of grief. When a child has a disability many of the dreams for the child and family are lost. Dreams may change; personal and family activities may be different, expectations for education may change, as well as many expectations for the future.

It is difficult to have hopes and dreams lost and it is the reason we grieve. We grieve for the child we thought we were going to have, we grieve for the opportunities that will never happen, we grieve because the path for our child will not be as smooth as we had hoped.

The challenge is to see hope, promise and value in the child, find acceptance and make meaning of a new life, find a new normal for a family and open the door for new hopes and dreams to emerge. It will take time, but the joys over the accomplishments of a child with a disability can be rich and fulfilling. There will still be dreams, just different ones.



Supporting Those Who Are Grieving

Grieving is a process that takes time and cannot be denied. People approach grief very differently. Some may face it head on and take very specific steps to deal with their grief. Others may let the pain and feelings come at will and work through them in a less intense, direct or obvious way. How a person will grieve is best left to each individual. The support being provided to someone who is grieving should complement that person's style and approach. Some options for supporting people who are grieving:

- Asking people what they need.
- Giving permission to grieve.
- Validating feelings and emotions.
- Listening to someone who wants to talk quietly about what has happened.
- Listening to someone who is angry and needs to vent about what has happened.
- Being a silent partner for someone who wants company, but silence.
- Providing books, videos, poems or newsletters on grief, feelings or other parent's stories about their grief if requested.
- Connecting them to an appropriate support group or a grief support group if requested.
- Suggesting appropriate speakers or workshops if requested.
- Sharing appropriate ideas and suggestions about how other parents have approached grief if requested.
 - Express their feelings through writing, drawing, painting or other creative outlets
 - Organize keepsakes
 - Work through grief very pointedly and with intent
- Suggesting and searching out spiritual support for people if requested.
 - Pastor, clergy or other spiritual leader
 - Appropriate materials that will provide spiritual support
 - A parent from the person's spiritual circle who might be a match
 - Meditation
 - Spiritual readings
- Suggesting and seeking out professional counseling if requested.
- Being patient and kind to those who are grieving.
- Checking in periodically by phone or visits. Support for those who are grieving doesn't end with one visit.



What was Helpful in Finding Hope?

As a parent mentor it may be helpful to expand your ideas for finding hope beyond your own experience, to better support other parents.

Discussion Notes:

