How Disability Affects the Family

The Loss of a Dream Results in Grief

When disability enters a family daily life drastically changes. Dreams and expectations are often shattered.

- If parents receive a diagnosis of disability for their child while they are still in the womb, they will inevitably find themselves already thrown into the role of advocate and caretaker. Before the baby is even born, the parents begin to shift their expectations of what life will look like after the birth of their child.
- If the disability occurs or is diagnosed at birth, there is a stark contrast between the joy that was anticipated and the reality of an uncertain future.
- If the disability occurs later in life, the individual and family are forced to consider which of their goals and dreams might never become a reality.

The death of a dream or expectation can cause grief that is every bit as real as grief resulting from the death of a loved one. Elisabeth Kübler-Ross, who studied grief and loss, describes five stages that are a common response to grief.

- Denial
- Anger
- Bargaining
- Depression
- Acceptance

For families impacted by disability these five stages can be circular. Acceptance of a diagnosis may be disrupted by the hope of a new therapy or treatment or the disappointment of a setback.

Caregivers Are Uniquely Challenged

The emotions of grief can be especially difficult for caregivers. As they process their own grief and care for their loved one they often experience:

- Exhaustion
- Isolation
- Financial strain
- Marital strain
- Questioning of their faith

Every Family Member is Affected

Every individual within the family unit will be uniquely impacted when one member is diagnosed with a disability.

- Parents usually carry the primary care-giving responsibility.

Every Family Member is Affected (continued)

- Marriages may become fractured resulting in one parent assuming the majority of the care-giving responsibilities.
- Siblings grow up with a unique family experience. They are often called into care-giving roles and must sacrifice their own needs because of the needs of their sibling who has a disability.
- Grandparents frequently desire to support the family but may not know how, especially if they require support and care themselves.
- Family traditions can be challenged, impacting both immediate and extended family.
- Many family members can experience a fear of what the future might bring.

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