

Grief and the Stages of Adaption

—
Texas Parent to Parent

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Grief



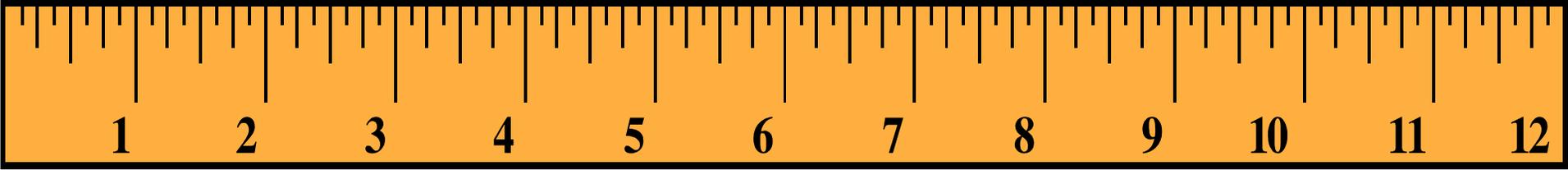
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The Five Stages of Grief According to Elisabeth Kubler-Ross From her book “On Death and Dying”

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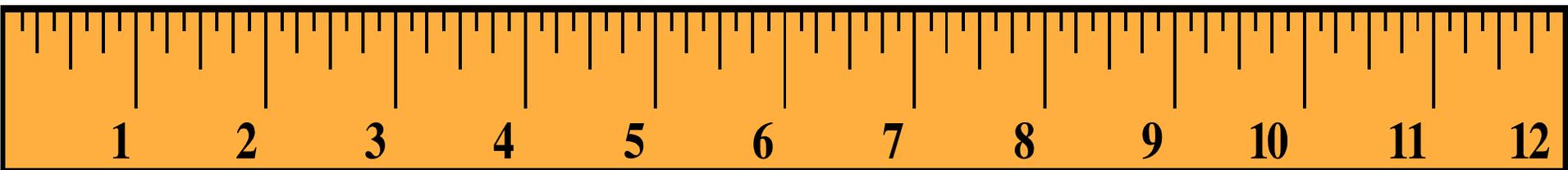
Denial

Anger

Bargaining

Depression

Acceptance



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Dr. Kubler-Ross identified other feelings associated with Grief!

- ❖ Numbness
- ❖ Sadness
- ❖ Guilt
- ❖ Fear
- ❖ Anxiety
- ❖ Physical Illness
- ❖ Feeling Victimized
- ❖ Confusion/Disorientation



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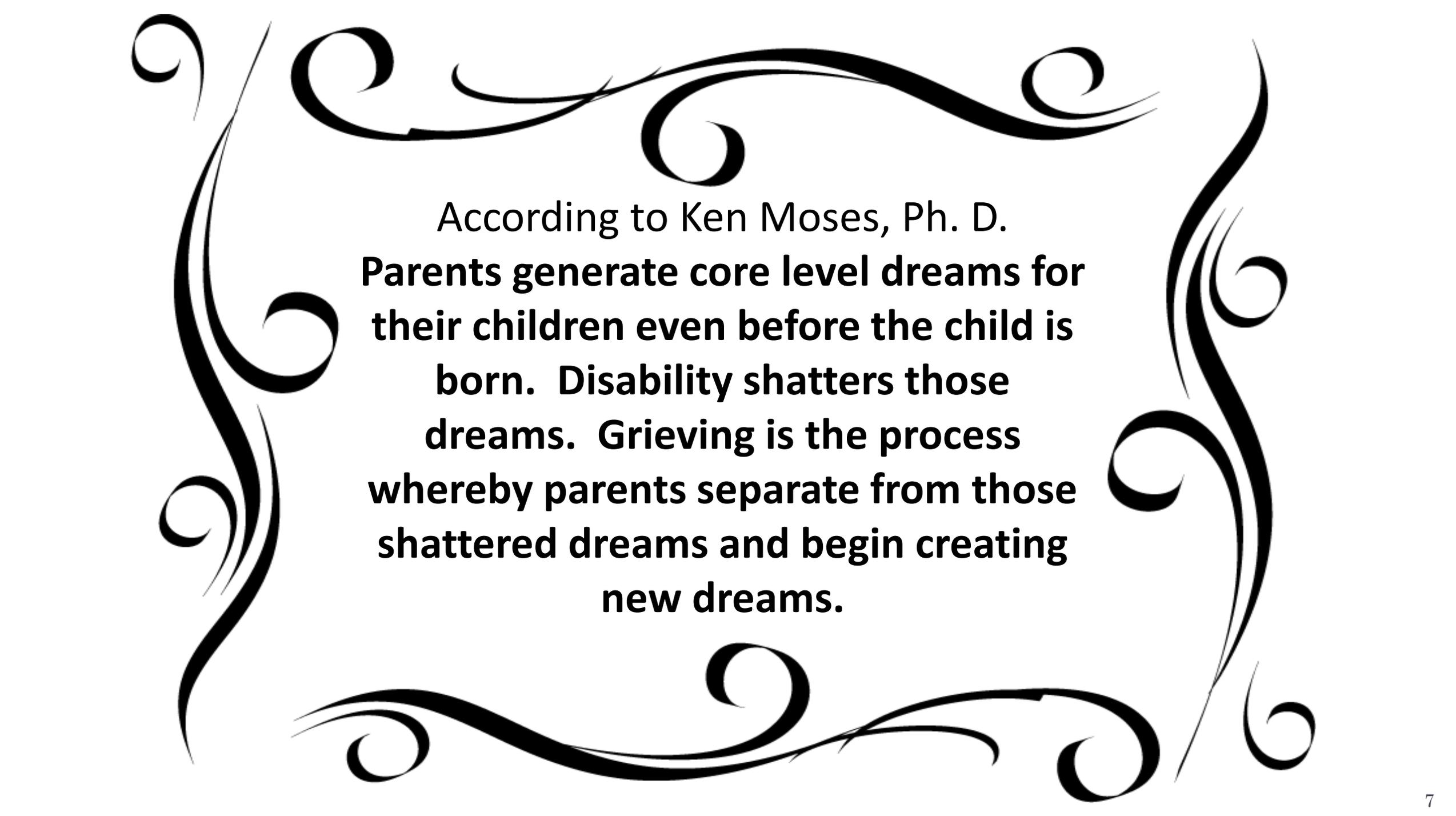


Grieving Process for Families of Children with Disabilities or Chronic Illness!



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A decorative border of black scrollwork and flourishes surrounds the text. The scrollwork consists of elegant, flowing lines that curve and swirl, creating a frame for the central text. The lines vary in thickness and end in small curls or loops.

According to Ken Moses, Ph. D.
Parents generate core level dreams for their children even before the child is born. Disability shatters those dreams. Grieving is the process whereby parents separate from those shattered dreams and begin creating new dreams.

The Grieving Process:



- It's an unlearned, automatic feeling process.
- It must be shared with a significant other.
- It may be a reoccurring cycle.
- Grieving is not an accepted state by society or sometimes even by the bereaved individual, either in specific or general.
- Grieving brings out the feeling states of denial, anxiety, fear, guilt, depression and/or anger.

The Feeling States

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Fear:



Fear brings out the issue of fight or flight. The flight takes you into denial and fight gives you the energy to reattach and generate new dreams.

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Denial:

Denial buys time to get you ready to deal with the loss, to prepare to deal with the issue of the disability, to find inner strength and external supports.



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Guilt:

Guilt helps people determine what they have control over and what they do not. “Do my actions, thoughts, and beliefs make an impact on what happens to me?”



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Depression:

Depression helps you redefine what it means to be a competent, capable, valuable, and strong person. You can feel depression without being depressed.



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Anxiety:



Anxiety mobilizes and produces the energy needed to make necessary changes.

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Anger:

Anger generates considerable energy to help you begin the necessary changes in your life.

It eventually leads you to identify the misconceptions and the truth about fairness and justice.



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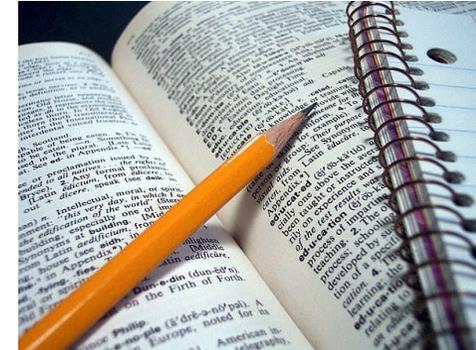
**It may be a
reoccurring cycle!**

Four Stages of Adaptation



Surviving

Searching



Settling in



Separating

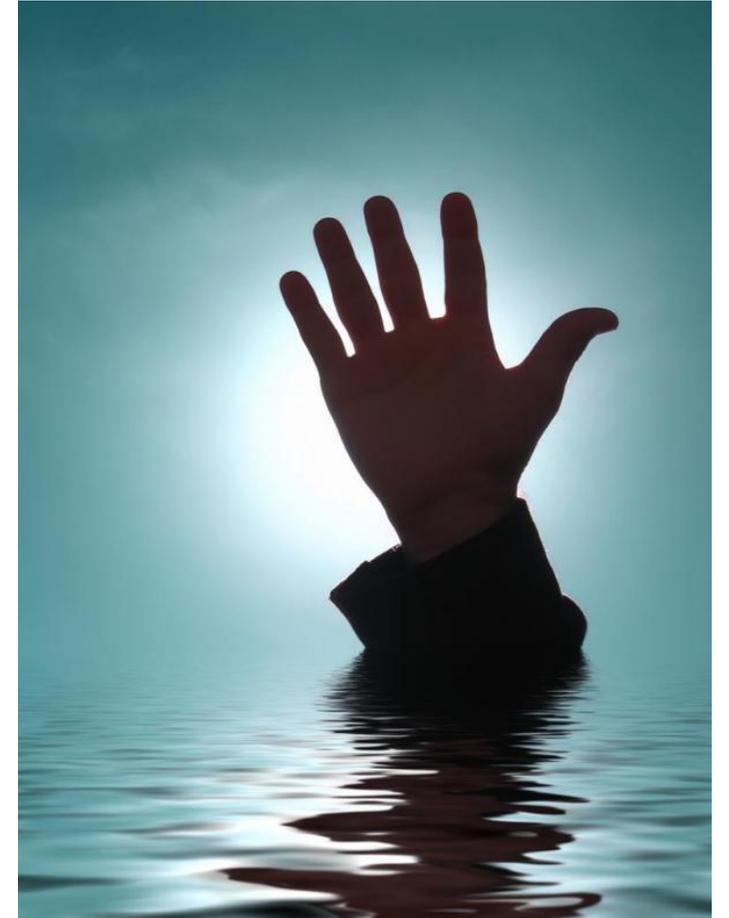


"Nobody's Perfect - Living & Growing with Children Who Have Special Needs" Nancy B. Miller, Ph.D., M.S.W., adapted by Laura J. Warren, Pilot Parent, Arc of the Capital Area)

SURVIVING:

What you do to keep going when you are feeling completely overwhelmed because something totally out of your control has taken away your child's equal chance at life.

You have something new and frightening to deal with, and you have to begin adapting to an uncertain future.



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Typical Reactions to Surviving

❖ Shock

- ❖ Bodily Stress & Symptoms: fatigue, physical symptoms (headaches, stomachaches, chest pains, loss of appetite, lack of sexual interest, etc.), feelings of weakness, fragility, and vulnerability
- ❖ Grief and Loss: grief, feelings of helplessness & aloneness, sadness, depression
- ❖ Confusion and Fear: confusion & chaos, uncertainty & ambiguity, fear, preoccupation with your child, worrying, asking questions that appear to have no answers

Typical Reactions to Surviving

(Continued)

- ❖ **Guilt and Self-Doubt**: guilt, self-absorption, self-pity, & self-doubt, shame & embarrassment
- ❖ **Anger**: resentment & envy, blaming, feelings of betrayal
- ❖ **Denial**: chosen denial, unconscious denial

“Being in a state of Surviving doesn’t last forever.

It just seems that way at the time.”



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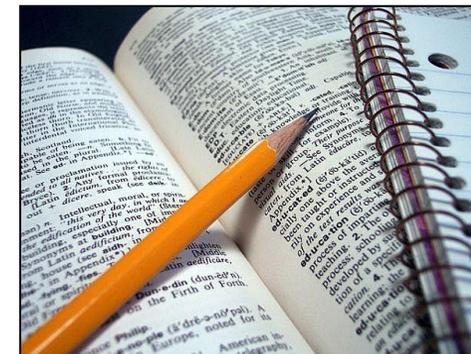
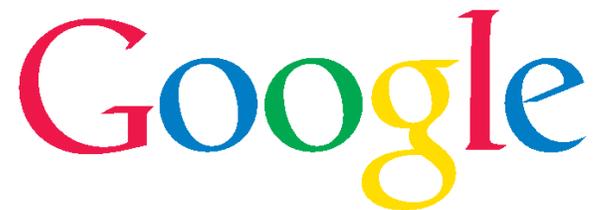
SEARCHING:

What you do when you are looking for answers for your child. You will probably have periods of searching during your whole life with your child.

There are two kinds of searching:

Outer Searching: looking for a diagnosis or services

Inner Searching: trying to find your identity as the parent of a child with special needs.



SEARCHING is a time of acting, of moving forward from your reactive stage of *Surviving*.

It is the awakening of a sense of control over your emotions and your life, and a time for seeking understanding about your child, your family, and yourself.



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SETTLING IN:



What you do when the frantic pace of searching lets up. You begin to choose your battles and balance your child's schedule and your family life. Not only has your outer searching subsided for a while, but more important, your attitude about it settles down.

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Settling In is seeing the world for what it is and seeing yourself for who you are. It is moving beyond the intense emotions of Surviving, feeling less of the sense of urgency of Searching, and gaining a greater sense of control and balance in your daily life.



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Some families are not able to enjoy the normality of feeling Settled In or this stage may be delayed, due to the following obstacles:

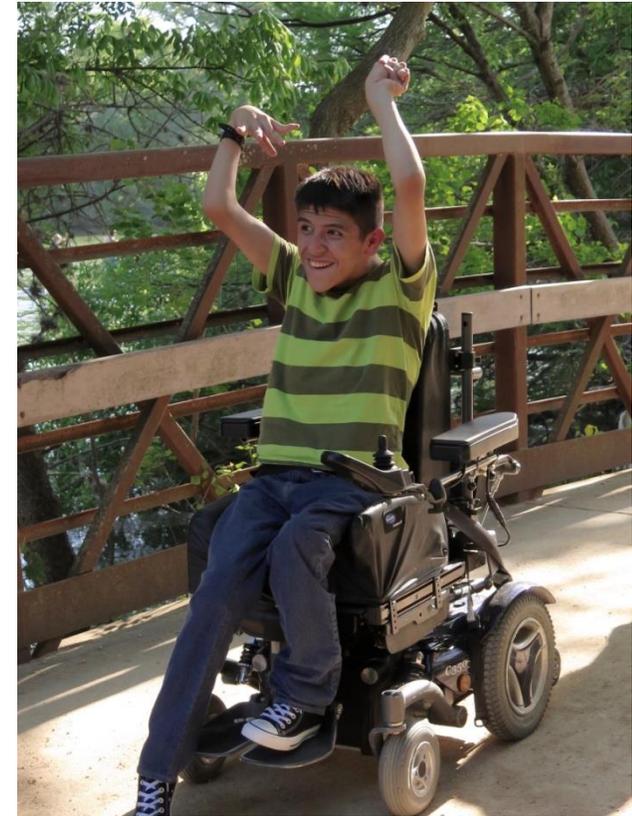
- ✓ continued medical crises or aggressive/self-destructive behaviors or the physical or mental health of any family member
- ✓ lack of financial resources or insurance or adequate insurance
- ✓ severe medical, learning, emotional, or behavioral problems; needs that families are not able to meet at home
- ✓ a marriage or relationship that cannot weather the storm
- ✓ single parenting resulting in juggling all the responsibilities
- ✓ old *Surviving* or *Searching* issues that come back into the foreground

SEPARATING:

What you do as a normal, gradual process that occurs in tiny steps throughout childhood.

When a child has a disability, the process may need to be altered or slowed down.

Extra parenting may be required - you may have to initiate separation, plan it, find it and make it happen.



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Obstacles to Separating



Child-Related Obstacles: special communication needs, social skill or safety issue

Parent-Related Obstacles: concerns about how much to protect or pull back, time or support team issues

Community Obstacles: lack of programs, lack of services or resources - funding, lack of transportation or scheduling problems, negative or hesitant attitudes in community

Siblings of children with disabilities often experience similar reactions to their own grief as they age.

Infants

Difficulty with sleeping and/or eating

Crying, anxious

6 months – 2 years old:

Crying, being inconsolable

Anger over change of schedule/routine

Trouble sleeping, tummy aches

Looking for the person, asking where they are

2 – 5 years

Repeated asking the same questions

Fear you may die or the death was their fault

Behavior inappropriate for age, clingy

Reactions of children continued...

5-10 years

Sad, feeling lonely, withdrawing

Feeling angry, trouble concentrating

Behavior may regress

Being brave/trying too hard, trying to control the situation/rituals (action > desired solution)

Adolescents and teens

Acting out, anger

Acting more childish/needing reassurance

Loss of self-esteem, poor concentration, decline
in school or work performance

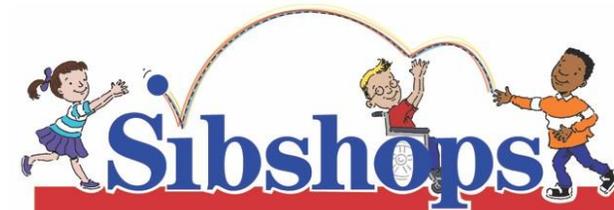
Emotional distance

Taking an adult, parent, or caregiver role, feeling
anxious/responsible about the future



How to help the Siblings cope with their feelings of grief

1. Make a point to spend individual time with sibling.
2. Find ways to allow them “help” and interact with their sibling.
3. Explain sibling’s disability in easy to understand language and be prepared to explain again as the children age.
4. Reassure young children that they did not cause nor can they catch their siblings disability.
5. School age children will be asked about their sibling, so begin those discussions early so they do not feel embarrassed, angry or confused when they have to tell others about their sibling.
6. Encourage them to discover their own interests.
7. Sibling rivalry is normal and the siblings should never be compared to each other.
8. Teens feel increased pressure to care for their sibling. Be sure to allow them enough freedom and space to set limits and maintain a sibling relationship vs. a caregiver relationship.
9. Consider a sibling support group or other outlets.



“You don’t recover from the events of life, you take them with you, you knit them in, you grow with them and around them; they become who you are; they are life itself; how else my life might have been is unknowable; and the truth is , I wouldn’t change it for any other.”

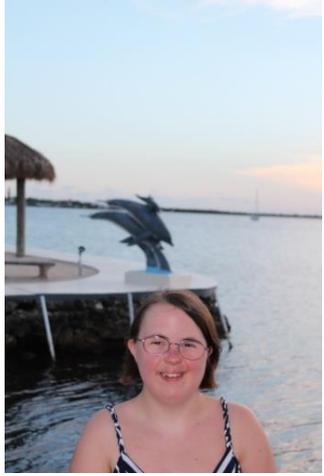


From Charles L. Mee’s book,
[A Nearly Normal Life, A Memoir](#)

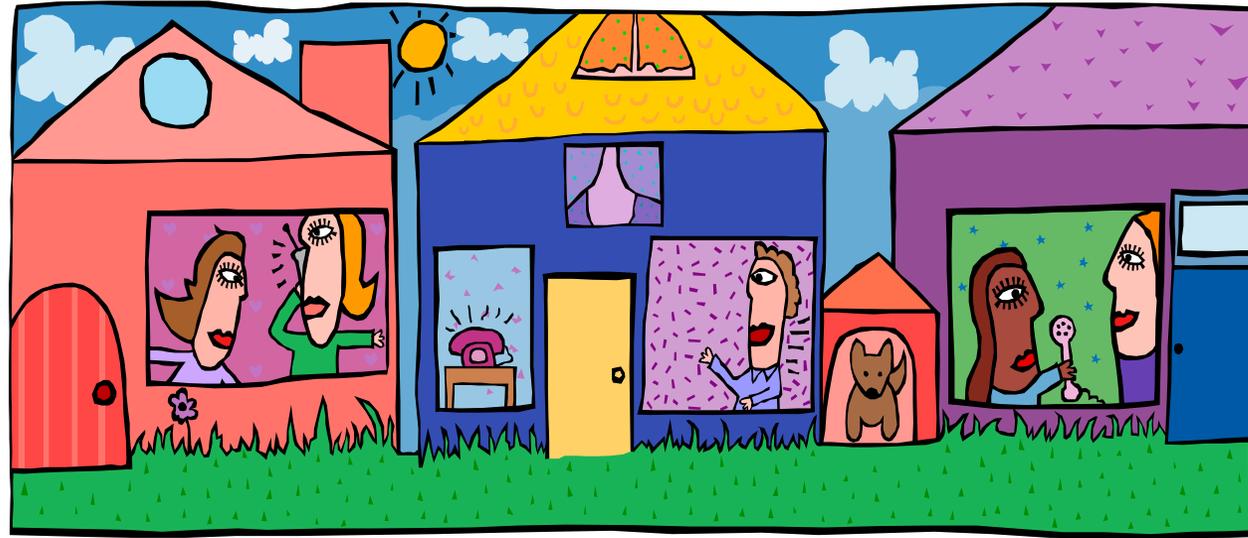
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Why we do it!!!!



Resources



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Texas Parent to Parent

www.txp2p.org; <http://www.txp2p.org/resources/>

Navigate Life Texas

www.navigatelifetexas.org; <https://www.navigatelifetexas.org/en/services-groups-events>

Parent Companion

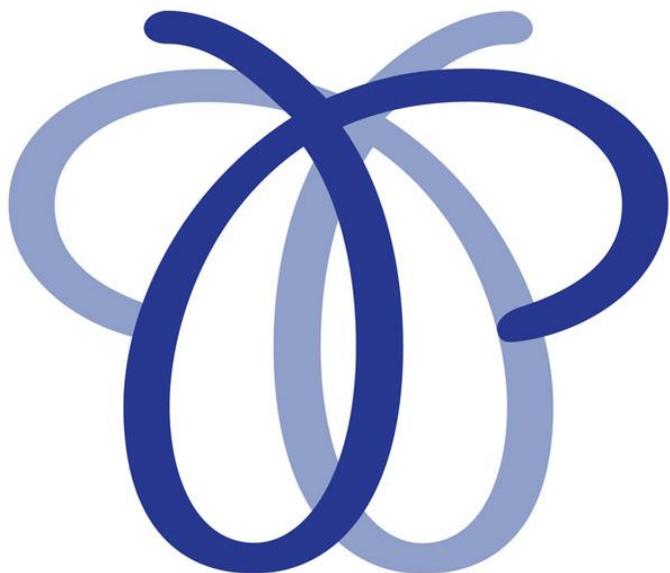
www.parentcompanion.org

http://www.parentcompanion.org/article/finding_services_and_resources_in_texas/First%20Step

Parent to Parent USA

www.p2pusa.org





Texas Parent to Parent

www.txp2p.org

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