

Going to Holland: Coping with Loss and Grief, and Accepting the New Normal

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“Grief is a strange mixture of joy and sorrow - joy to be alive and sorrow at the loss of your loved one. Your courage is not the absence of fear and pain, but the affirmation of life despite the fear and pain.”

~Dr. Earl Grollman



Grief

- Grief is a natural and normal reaction to loss and change
- It is a response that is physical, emotional, psychological and spiritual
- Grief is a *universal phenomenon*



Stages and Intervals of Grief

Stages

- Shock or Disbelief
- Denial
- Anger
- Bargaining
- Guilt
- Depression
- Acceptance and Hope

Intervals

- **Early Grief** -shock, numbing, denial and anger.
- **Acute Grief** –intense longing for the loved one, distress, tearfulness, restlessness, insomnia, preoccupation with thoughts of the loved one, a sense of the presence of the loved one.
- **Subsiding Grief** -the ability to endure acute grief and begin moving forward.





What Happens When We Grieve?

- The grief reaction of each person is highly personal
- There is no set list of what one should or should not feel
- There is no certain time frame in which one “gets over it”
- Grieving people often experience:
 - Anger
 - Guilt
 - Anxiety
 - Sadness
 - Despair
 - Difficulty sleeping
 - Changes in appetite
 - Health complications



The Right Way to Grieve?

- There is a correct amount of time to grieve...the amount of time you personally need!
- Grief encompasses many feelings and emotions that come when they come. Feel what you feel, when you feel it.
- You are in charge of your grief journey.
- It takes incredible strength to allow others to walk with you in your grief journey.
- There are many different ways of grieving.
- There are very few rules in grief.
- Be compassionate with yourself during your grief process.



Anticipatory Grief

- The grief process that a person undergoes before a loss actually occurs
- Anticipatory grief includes symptoms of regular grief – sadness, anger, isolation, forgetfulness, and depression. These emotions are often coupled with the exhaustion that comes with being a caregiver
- This process is normal
- Acknowledge the losses
- It does not mean that you are giving up
- Communicate and connect
- Take care of you
- Seek help if necessary



Complicated Grief

- Signs and symptoms of complicated grief may include:

- Intense sorrow and pain at the thought of your loved one
- Difficulty focusing on areas of life not related to the loss
- Extreme focus on reminders of the loved one or excessive avoidance of reminders
- Intense and persistent longing
- Problems with acceptance
- Numbness or detachment
- Bitterness about your loss
- Feeling that life holds no meaning or purpose
- Irritability or agitation
- Inability to enjoy life or think back on positive experiences with your loved one
- Difficulty carrying out normal routines
- Withdraw from social activities
- Experience depression or deep sadness
- Have thoughts of guilt or self-blame
- Believe that you did something wrong or could have prevented the death/loss
- Have lost your sense of purpose in life
- Lack of trust in others
- Thoughts of suicide



Grieving when raising a child with special needs



Living with Loss

- Experiencing concurrent losses
- Grieving is an ongoing feature of raising a child with special needs
- Experiencing grief over time and often having intense wishing for what might have been
- Secondary losses
- Grieving for yourself and lost opportunities
- Social isolation as friendships change, and extended family withdrawing in response to the child's disability





Grieving in the Midst of Difficulty and Intensity



Outside Stressors that Impact Caregivers of Children with Special Needs



- Managing daily needs of the family in addition to:
 - Medical and therapy appointments
 - Teacher meetings
 - Advocating for services
- Siblings feeling overlooked or heavily relied upon
- Financial stress
- Limited support



Living with Stress

- Many children with special needs have challenging behavioral disturbances or complex physical needs
- Some children with special needs also have psychological disturbances or adjustment difficulties
- Some caregivers may experience difficulty with health professionals who do not understand these complexities



Factors that may Interfere with the Grief Process



- Avoiding emotions
- Feeling overwhelmed and exhausted
 - Use of alcohol or other drugs
- Unresolved grief from a previous loss
 - Judgmental relationships
 - Resenting those who try to help





Grief and Trauma

- Caregivers may experience trauma at various times:
 - Diagnosis
 - Various forms of treatment
 - Hospitalizations or surgeries
 - Life threatening complications
- Caregivers may have so much to deal with that their own self-care is neglected
- Some caregivers may be more susceptible to traumatic stress reactions:
 - Where there are multiple concurrent stressors (stressors weaken resources)
 - Caregiver's own difficult childhood experiences or previous traumas



Differentiating Trauma from Grief

- **Re-experiencing Symptoms:**
 - Mentally replaying trauma while awake or asleep
- **Avoidance Symptoms:**
 - Avoids trauma-related activities, places, thoughts or feelings
- **Numbing Symptoms:**
 - Loss of emotions, especially positive ones
- **Arousal Symptoms:**
 - Difficulty concentrating and sleeping, and a heightened sense of being on guard



Grief and Relationships

- Recognize that your grieving processes may look different
- Be careful about projecting your emotions onto your partner
- Try not to continually offer solutions to your partner's grief
- Don't let your partner be your only source of emotional support
- Keep a list of names on speed dial
- When verbal communication is too painful, write to one another
- When possible, look for feasible ways to ease your partner's pain
- Listen to one another closely and validate each other
- Invest in your relationship
- Never hesitate to seek help



Letting Go and Building a New Normal



- Create new routines
- Embrace a new family structure
 - Plan new activities
 - Share your stories
- Accept what you cannot change
 - Shift your perspective
 - Celebrate all milestones
- Build emotional resiliency through new memories



Building Resilience: The Courage to Come Back

- 1. Make connections
- 2. Avoid seeing crises as insurmountable problems
- 3. Accept that change is part of living
- 4. Move toward your goals
- 5. Take decisive actions
- 6. Look for opportunities for self-discovery
- 7. Nurture a positive view of yourself
- 8. Keep things in perspective
- 9. Maintain a hopeful outlook
- 10. Take care of yourself



A Time to Heal



- Take time for yourself
- Express and share your feelings of grief
- Seek out parent and peer support groups
 - Explore intervention programs



Sharing Our Stories

- Learning to love your new normal...How have you done it?





"Grief never ends... but it changes.
It's a passage, not a place to stay.
Grief is not a sign of weakness, nor
a lack of faith...
It is the price of love."





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