



Between a Rock and a Hard Place: Helping Young People Cope with Grief, Loss and the Reality of HD

Allison White Twente, Ph.D.
Westhampton Family Psychologists
Richmond, Virginia

Presenter Disclosures

No relationships to disclose or list



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Living in limbo:
Sometimes it feels like there's no where to run



Loss, Bereavement & Grief

- Loss – when an event is perceived to be negative by the individual involved and it results in long term changes in social situation, relationship or way of viewing the world & oneself.
- Bereavement – the period after a loss during which grief is experienced and mourning occurs.
- Grief – the normal process of reacting to a loss which may be physical, social or occupational. Emotional reactions include anger, guilt, anxiety, sadness & despair. Physical reactions include sleep problems, changes in appetite, physical problems & illness.

Losses Lived in Huntington's Disease

- HD involves a series of interrelated losses
- Each person in the family experiences multiple, personal losses
- Tangible losses: motor control, independent living skills, speech
- Material losses: loss of a job, changing living circumstance
- Symbolic losses: changing roles in a family
- Psychological losses: changes in self-worth, identity, sense of control, loss of the future as hoped

Cumulative Losses in HD

Stressful events → →

→ → Multiple Losses

Each loss = multiple
consequences

Physical & Mental
deterioration

Losses involving careers,
finances, love life, ability to
do normal chores, engaging
in pleasurable joint activities

Family losses include
stigma of being (with) a
chronically ill person
Fears of genetic testing

On Being a Pre-vivor

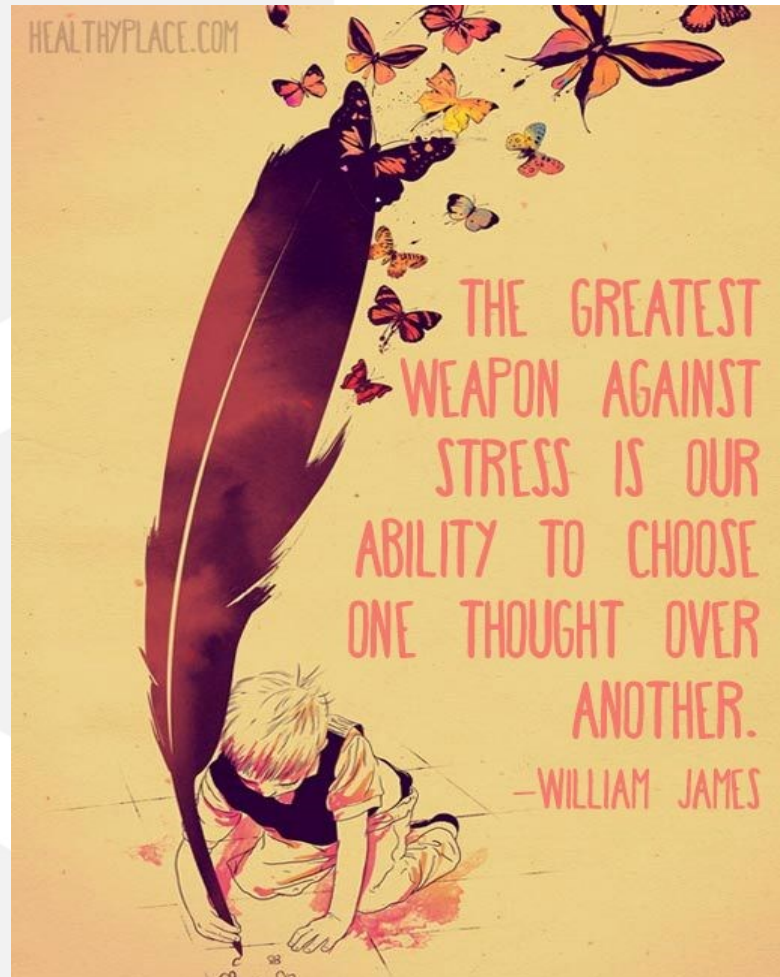
- Term has been increasingly used in the cancer community
- Related to an inherited, genetic **Pre**-disposition to a disorder
- Individual has increased stress/worry about eventually becoming symptomatic
- Life with the knowledge that you could become sick
- How to Cope as a Previvor for HD?

Worrying is like
walking around
with an umbrella
waiting for it
to rain.



Experience of Stress is Cumulative

- Changes observed in a Parent's role & function
- Friction between Parents
- ? Separation of Parents
- Change in School/Friends
- Altered roles within the home
- New Babysitters/child care situation
- Change in Financial Situation
- Change in Responsibility at Home
- Change of Roles Within a Family
- Increased pressures, expectations for all family members



Reactions to Loss = Grief

- Grief consists of emotional, psychological and physical dimensions
- Does Family Grief exist? Or is grief an individual process?
- Ambiguous loss – someone is there but not there
- Anticipatory grief – grieving the loss of a person's “former self”; missing the person before they die
- Grief at time of death – mixture of feelings including relief

Grief is like the ocean;
it comes in waves,
ebbing and flowing.
Sometimes the water is
calm, and sometimes it
is overwhelming. All we
can do is learn to swim.

Vicki Harrison

How Young People Grieve

Q: At what age are children able to mourn?

A: “Any child old enough to love is old enough to mourn” (Alan Wolfelt)

Children tend to grieve in bursts, interspersed with play and normative activity.

Common signs to help recognize grief in young people:

- separation anxiety
- regression
- impatience
- inattention
- protectiveness

COPING WITH LOSS: HOW TO HELP YOUR CHILD



FOR EVERYDAYFAMILY.COM



Huntington's Disease
Society of America

How Children & Youth Grieve

- Preschoolers (2-4 years)
lack comprehension of death or permanence, literal understanding, acting out of feelings
- Elementary Schoolers (5-10 years)
experience full range of emotions, limited life exposure, assume they are to blame, worries about who will care for them
- Middle Schoolers (11-13 years)
social dimension of death and its impact on family, friends & school emerges, resentments of new relationships likely
- High Schoolers (14-18 years)
philosophical questions about the meaning of death, magnified experience of normal adolescent behavior & moods
- Young Adults (19 – 25 years)
questions about assuming adult roles, making life decisions

What Young Adults Want Parents to Know

- Don't say: "I know how you feel" or "Everything will be ok"
- Don't make us talk
- Don't say "Your (insert loved one) would have wanted this."
It instills guilt.
- Be considerate of our emotions
- Remember we want to be kids; don't give us parental duties
- Realize that everyone reacts differently; we're all individuals, don't assume you understand us
- Don't force counseling on us; let us ask if we wish for help
- Help us ease into life transitions
- Be patient with us
- Don't date or remarry to replace the person who died

Ways to Increase Communication

- Consider alternative methods of communication
- Face to face talking can feel intrusive
- Don't bombard youth with questions or reactions
- Written notes or a communication book can be helpful
- Texted check ins? Emojis?
- Description of Care Tags

Comfort Zone Camp



- Started in 1998, CZC is a bereavement camp for children aged 7 – 17 (with some programs for youth - age 22 & families)
- Based in Richmond, VA camps are also held in Massachusetts, Connecticut, North Carolina & California
- www.comfortzonecamp.org
- Volunteering for weekend camps, Big Buddies & Healing Circle leaders needed
- Hello Grief.org



Care Tag Activity



- Adults & kids can list unique ways they like to be taken care of by others
- Handle delicately
- Don't be rough
- Be encouraging
- Understand I want to be alone
- Give me hugs
- Pizza!
- Make me giggle
- Take a walk with me

Dilemmas in Dealing with HD

- Who can you trust to lean on?
- Do you want others to know the details?
- Who are you most worried about in your family?
- Can peers understand the situation?
- Fears of burdening a surviving parent or caregiver
- Caregiver/ compassion fatigue
- Anger & resentment at other's lives
- What stinks?
- Guilty feelings in wish for a normal life

Grief: Normative Grief

- Grief encompasses a wide range of emotions, cognitions and behaviors
- Some painful thoughts → to intense & disruptive sadness, loneliness, anger, guilt, difficulty concentrating, social withdrawal, overwhelmed by loss
- In months after loss, auditory and visual hallucinations of loved one are possible
- Positive emotions such as relief, peace & happiness are also common

Grief: Normative Grief

- Grief does NOT proceed through linear stages
- Grief is complex & comprises a broad spectrum of feelings, thoughts and behaviors
- Grief varies among and within individuals
- **Research shows that laughter and smiling when discussing a loved one predicts a reduction in grief symptoms over time**

Grief: Normative Grief

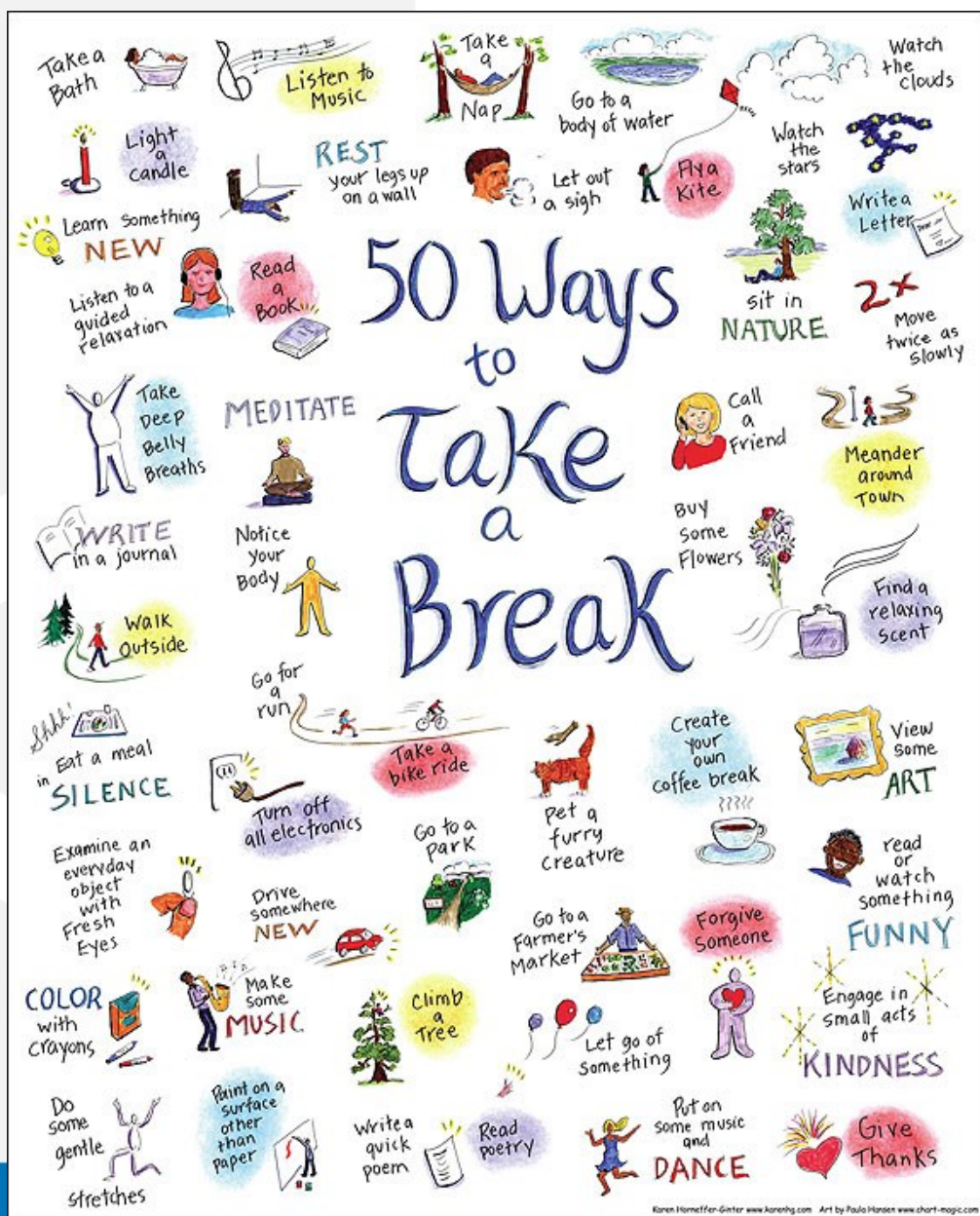
- Some experience elevated levels of distress, the pain and disruption of loss initially may feel overwhelming but will subside in intensity over time for most individuals
- As grief progresses, elements of sadness & pain can remain
- Trajectory of grief symptoms will vary among individuals
- Over time grief becomes more intermittent, less interfering, and is balanced with a sense of interest and purpose in life

**DO NOT CONFUSE MY BAD
DAYS AS A SIGN OF WEAKNESS.
THOSE ARE ACTUALLY THE DAYS
I AM FIGHTING MY HARDEST.**



Coping Techniques

- Description of Positive vs Negative Coping
- Coping A-Z Exercise
- Mood Boosters
- 50 Ways to Take a Break
- Customize your own Care Tag



Karen Horneffer-Ginter www.karenh.com Art by Paula Hansen www.short-magic.com

Increasing Positive Thinking

Mindfulness & Relaxation Response

- Relaxation Training
- Other Mind-Body Approaches (breathing, yoga)
- Activities to “break set”
- “Flow” Activities
- Set Reasonable Goals/Time Management
- Outdoor Recreation
- Media/ Screen Limits
- Mindfulness & Savoring Activity

Cognitive-Behavioral Therapy Helpful for Managing Anxiety

Children (& adults) have the skills to overcome worry –
They simply need help fine tuning when to use:

- Ignoring certain thoughts
- Bossing back anxious thinking
- Thinking creatively to solve problems
- Getting used to things that are hard
- Fact-check claims that worries make

Cognitive Restructuring Technique

WHAT CAN I SAY TO MYSELF?	
INSTEAD OF...	TRY THINKING...
-I'M NOT GOOD AT THIS	-WHAT AM I MISSING?
-I'M AWESOME AT THIS	-I'M ON THE RIGHT TRACK
-I GIVE UP!	-I'LL USE SOME OF THE STRATEGIES I'VE LEARNED
-THIS IS TOO HARD	-THIS MAY TAKE SOME TIME AND EFFORT
-I CAN'T MAKE THIS ANY BETTER	-I CAN ALWAYS IMPROVE; I'LL KEEP TRYING
-I CAN'T DO MATH	-I'M GOING TO TRAIN MY BRAIN IN MATH
-I MADE A MISTAKE	-MISTAKES HELP ME IMPROVE
-I'LL NEVER BE AS SMART AS HER	-I'M GOING TO FIGURE OUT WHAT SHE DOES AND TRY IT
-IT'S GOOD ENOUGH	-IS THIS REALLY MY BEST WORK?

Treatment Resources – for Young People

- Chansky, Tamar (2014). *Freeing Your Child from Anxiety*. New York: Harmony Books.
- Foxman, Paul (2007). *Dancing with Fear: Controlling Stress and Creating a Life Beyond Panic and Anxiety*. Alameda, CA: Hunter House, Inc.
- Greenland, Susan K. (2010). *The Mindful Child*. New York: Simon & Schuster.
- Huebner, Dawn (2006). *What To Do When You Worry Too Much: A Kids Guide to Overcoming Anxiety*. Washington, DC: Magination Press.
- Rapee, Ronald M. et al. (2008). *Helping your Anxious Child: A Step-By-Step Guide for Parents*. Oakland, CA: New Harbinger Press.

Mental Health and Resilience

Happy People...

live minimally, tell the truth,
never make excuses, take time to listen,
don't hold grudges,
speak well of others, choose friends wisely,
establish personal control,
dream big,
see problems as challenges,
nurture social relationships, avoid social comparisons
treat everyone with kindness,
exercise,
don't sweat the small stuff,
accept what can not be changed,
meditate,
avoid seeking approval from others,
express gratitude for what they already have,
eat well,
wake up at the same time every morning,
and get absorbed
in the "Now".

Can We Teach/Train Resilience?

“If you are able to look back on your life and tell yourself a story about your stress that includes how you learned from it, it continues to create a narrative of strength, learning and growth”

Kelly McGonigal, Stanford Univ

Stress can make you strong

McGonigal's research shows that rather than fearing stress, we need to view it differently – embrace an opportunity to grow strong

- Caring for others builds resilience
- Having a purpose in life decreases stress
- Viewing stress response as helpful can build courage

Grief: Complicated/Prolonged Grief

- A minority of bereaved individuals experience more extreme grief symptoms
- Substantial, persistent distress and impairment despite the passage of many months or years
- Similar to other psychiatric diagnoses, the symptoms must be associated with significant distress or impairment

Prolonged or Complicated Grief Reactions

- Symptoms persist or grow rather than diminishing over time
- PGR found to be from 10% - 20% of the population
- Multiple risk factors

Prolonged Grief Reaction in

Prolonged Grief Reaction

Risk Factors for PGR

- Prior trauma or loss
- History of mood & anxiety disorders
- Insecure attachment style
- Being a caretaker for the deceased
- Violent cause of death
- Lack of social support
- History of separation anxiety in childhood

Prolonged Grief- ICD-11 Proposed Criteria

When death of a close other & yearning for deceased daily,
5 or more of the following daily or to a disabling degree:

- Confusion about one's role in life/or a diminished sense of self
- Difficulty accepting the loss
- Avoidance of reminders of the reality of the loss
- Inability to trust others since the loss
- Bitterness or anger related to the loss
- Difficulty moving on with life
- Emotional numbness since the loss
- Feeling that life is unfulfilling, empty or meaningless since the loss
- Feeling stunned, dazed or shocked by the loss

Prolonged Grief: ICD-11 Proposed Criteria

Criteria also include:

- At least 6 months have passed
- The disturbance causes clinically significant impairment in social, occupational and other important areas of functioning
- The disturbance is not better accounted for by major depression, generalized anxiety disorder or post-traumatic stress disorder

Assessment of PGR

- Inventory for Complicated Grief (ICG) & the Brief Prolonged Grief – 13 (Prigerson et al.; 2009)
- In Primary Care Settings, the Brief Grief Questionnaire (BGQ; Ito et al.; 2012)
 - BGQ measures 5 symptoms on a 3 point severity scale
 - “How much is grief interfering with your life?”

Assessment of PGR

- When PGR is present – assess for Risk
- Prolonged Grief is associated with a 6 – 11 times higher rate of suicidality

Treatment for Prolonged Grief

- Pharmacotherapy – SSRI's found to be effective
- Psychotherapy – especially CBT
 - Individual Psychotherapy
 - Group Psychotherapy
 - Internet-based treatment with email communication
 - Behavioral activation and social re-engagement helpful

Prolonged Grief & Children

- Minimal empirical research into prolonged grief in children
- Melhelm & Porta, 2014 describe 3 classes of kids:
 - Class 1: Rapid resolution of grief symptoms
 - Class 2: Gradual decrease in grief symptoms
 - Class 3: High & sustained grief symptoms 33 months after loss

Prolonged Grief in Children

- Children in both Class 2 & Class 3 were at increased risk for depression & functional impairment
- Bidirectional relationship between prolonged grief and psychiatric vulnerability
- One of the most consistently reported findings is that caregivers' well-being after parental bereavement is a significant predictor of children's and adolescents' well-being.

Prolonged Grief in Families

- Complicated grief in the surviving parent and the offspring was potent in predicting depression
- Clinical implications regarding intervention and prevention
- Imperative to assess the surviving parent
- Family interventions should be considered

Resources for Helping Youth with Loss

Cohen, Jill et al. (2006). *Treating Trauma and Traumatic Grief in Children and Adolescents*. The Guilford Press.

Hughes, Lynne B. (2005). *You Are Not Alone: Teens talk about life after the loss of a parent*. Scholastic Inc.

Trozzi, Maria (1999). *Talking with Children About Loss*. Penguin Putnam, Inc.

Wolfelt, Alan. (2001). *Healing a Teen's Grieving Heart: 100 Practical Ideas for Families, Friends and Caregivers*, Companion Press.

www.childrengrieve.org (National Alliance for Grieving Children)

www.HelloGrief.org (Comfort Zone Camp sponsored)

www.caregiver.org (Family Caregiver Alliance)

“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.”

Author unknown