Presenter Disclosures
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The following personal financial relationships with commercial interests relevant to this presentation existed during the past 12 months:

No relationships to disclose

Huntington’s Disease Society of America
You are your own expert
And HD brings us together, so it might look like this

Ambiguous loss
The loss of someone important to you
Supporting people who are grieving
Supporting children who are grieving
Anticipatory grieving
Complex grieving
Grieving as a result of test results, yours's or someone else’s
What is grief

emotional

physical

cognitive

spiritual
Physical impact of grieving

Overall lack of energy
Sleeping too much or too little or have difficulty falling asleep
Withdraw socially and from activities
Crying
There is no right and wrong way to grieve
Grieving is not linear
There is no time limits

There is not set time for how long you grieve
There is no set time how long a person needs to spend in each phase
You may need to go back and forth between phases
Different people take different amounts of time
There isn’t a benefit to rushing grieving
Sometimes you need assistance from outside sources if you are feeling stuck
• It is very important to tell your story over and over again as you process your grief
• At the same time it is important to figure out who to tell your story to
  • Some people want to hear it once
  • Some people will be open to hearing to several times
  • Some people will listen over and over again.

• And some people just aren’t good listeners at all.
  • But they may be for you in other ways
  • And they may care greatly for you and feel your pain.
    • They just aren’t good listeners
      • and there might be other reasons
Learn to read people
Some times good listeners are found in other places

- A more distant acquaintance
- A person you have recently met
- A professional who is trained to listen and help you process
- Support group members
And you can find formal settings where you will find people who will listen to your story

- The 2017 National Convention of HDSA
- HD support group
- HDSA state conventions
- Support groups
  - HD
  - Caregivers’ group
  - Grief group
- Therapy
On-line support

“To Damn Young”
HD-YO
“Caringbridge”
You can’t control how others will react to what you tell them about your loss or your grieving.
You need to decide when it is good to share and when it isn’t

You get to share what you want to

• As much as little
It may feel scary to bring up your loss

You may feel vulnerable

It is a delicate topic and you can give some thought on how you want to present your loss,

You get to determine the when and the how
Ambiguous Loss
Type Two: Physical presence and a psychological absence
Type One: Physical absence and a psychological presence
• Physically present and psychologically absent
• They are there and yet they aren’t
• The person takes energy and your needs go unmet
• The loss may happen in stages over time
- Ambiguous loss is highly stressful
  “the most stressful loss there is”

can be very confusing

it can go on for a long time
• Ambiguous loss significantly impacts family functioning
  
  • Cause confusion in family dynamics
  
  • Can cause a change in roles within the family
  
  • Freezes family members and doesn’t allow them to move forward
ambiguous loss can go on and on like a roller coaster
• At the same time you may feel like you are walking on egg shells as a result of changes to your loved one’s personality,
Ambiguous loss
Impact on the care giver

• Depression
• Anxiety
• Somatic symptoms (but make sure they aren’t real symptoms)
• Lack of energy
• Withdrawal socially and from activities
“So What do You do Dear”
• Acknowledge ambiguous loss
• Learn more about ambiguous loss
• Have a therapist
• Family therapy
• This might be a good time to have your children develop a relationship with a therapist
• Participate in an HD support group
AMBIGUOUS LOSS
LEARNING TO LIVE WITH UNRESOLVED GRIEF

PAULINE BOSS
And you can spend time with other families experiencing ambiguous loss
The 4 Tasks of Grieving
William Warden PhD
Task 1

“To accept the reality of the loss”

Accepting intellectually and emotionally that the person has died and will not return or the traumatic event has happened.

The funeral or other ritual
Task 2

• “To process the pain of grief”
  
  • This is potentially painful stage is dedicated to having a better future.
  • It is easy to avoid this hard work
Task 3

• “Adjusting to life without your loved one”
  • External internal, and emotional adjustments
  • Accept new roles, changes in lifestyle, possibly living situation
  • Accepting that their loved one is no longer there allows the person to move on to their new future
Task 4

• “To find an enduring connection with the deceased in the Midst of Embarking on a new life”

This is not forgetting the deceased

• It is finding a way to stay connected and moving on at the same time

• Enjoying life and having memories and feelings for
You likely will grieve differently than the other people who experienced the same loss.

And the stages you go through may take each individual different amounts of time.
• Overall males and females grieve differently
  and this can be very difficult for a couple

• There are differences between cultures
  and there are still differences between people who have similar cultural beliefs

• Some people are introverted and some people are extraverted and this impacts how they grieve
Grieving is not linear
•
  • Stages are not completed for ever
    • You can and likely will need to return various stages

• Grieving is a life long process

• One or more of these stages may need to be revisited through out a person’s life
• What are some other things that influence how a person might grieve?
GRIEF
• You can listen to other people’s grief and gather words
  listen to suggestions that have worked for them

• But you have to grieve your own way
• Each developmental stage have special needs
• And each developmental stage has tasks to go through that are a necessary part of development
  • And this will provide challenges in adjusting to ambiguous loss and grieving
• Children pick up on the emotions of their parents
  • They will try to meet their expectations
  • They may act out their parents feelings
• Children sometimes act out to deflect from family stress
For adolescents

These needs and tasks may be in conflict with grieving together with family at least some of the time.
It can be a balancing act for a parent
Your own grieving
New roles and responsibilities
Your own grieving
This is a good time to reach out

• A therapist for your child
  • And establishing with a therapist early is beneficial
• Work closely with your child’s school
  • keep them up to date.
  • Use resources available through school
BIBLIO THERAPY
Make Web-sites available

• “Too Damn Young”
• “HD-YO”

• Remember adolescents
  • Need peers who have similar experiences
  • Are in the process of separating,
  • May want privacy or private time
From the Heart
REMEMBER SELF CARE

• EAT
• SLEEP
• FLUID

• ACCEPT SUPPORT AND
  • COMFORT FROM OTHERS

• EXERCISE or PHYSICAL MOVEMENT
• PURSUE INTERSTS
• Be easy on yourself
• Accept comfort and support from others

• Accept offers of help

• Reach out to others and let them know you are interested in getting together
Everything gets magnified

Acts of kindness seem huge

And absence and lack of availability seems huge too
Grieving may impact judgment

- If you can avoid having to make big decisions
- Delay judgment about new people you meet
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HDSA’s 32nd Annual Convention
Schaumburg, IL
June 22-24, 2017
Visit HDSA.org/convention for more info