

# Presenter Disclosures

Nina Ross LICSW-MPH

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

No relationships to disclose



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**

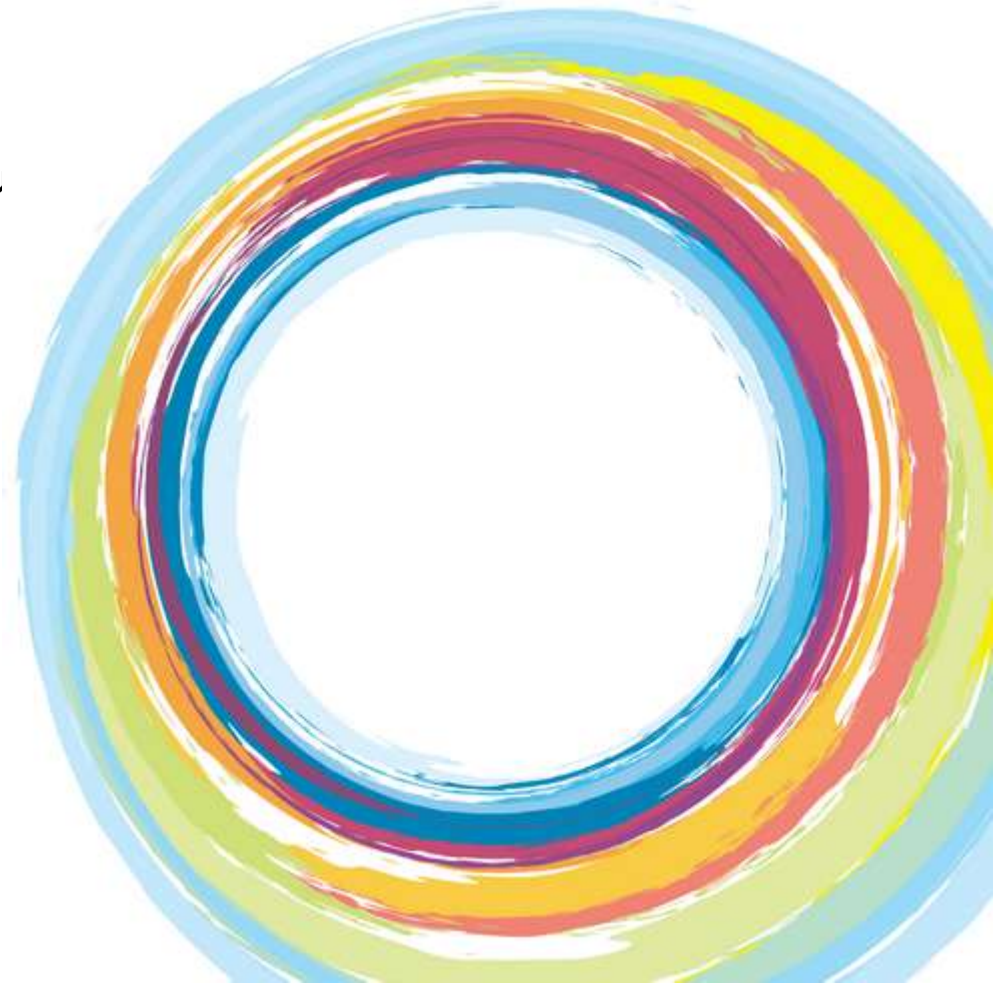
Supporting people who are grieving

**Supporting children who are grieving**

Anticipatory grieving

Complex grieving

Grieving as a result of test results,  
yours 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

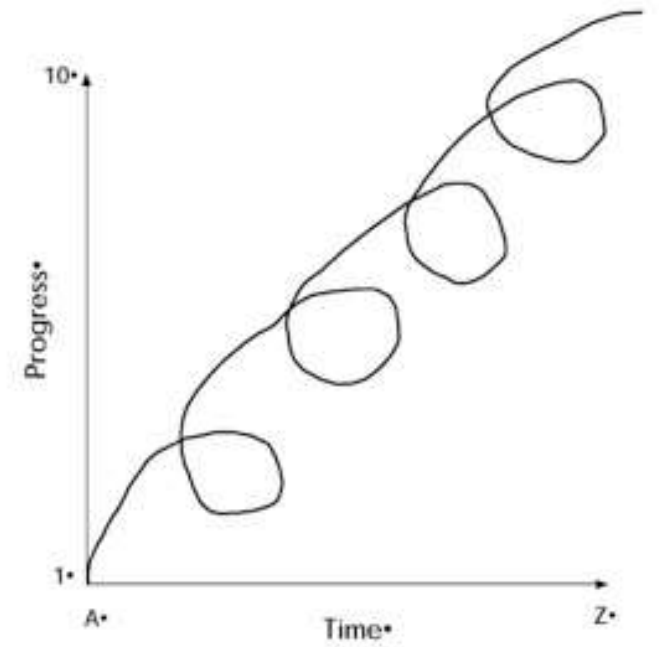
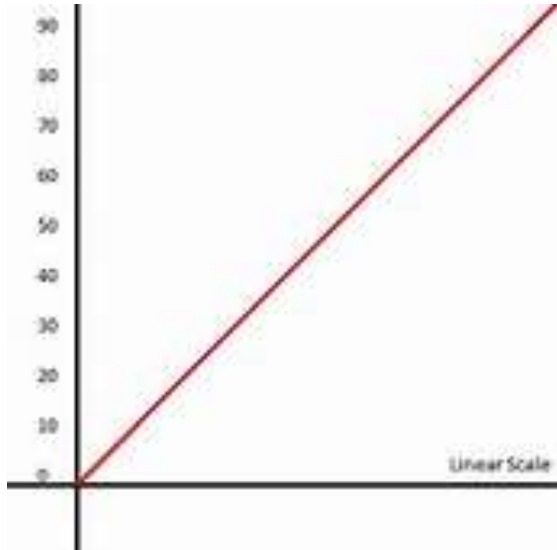




# There is no right and wrong way to grieve



# Grieving is not linear



Typical



# 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 you 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 ; this impacts how they grieve



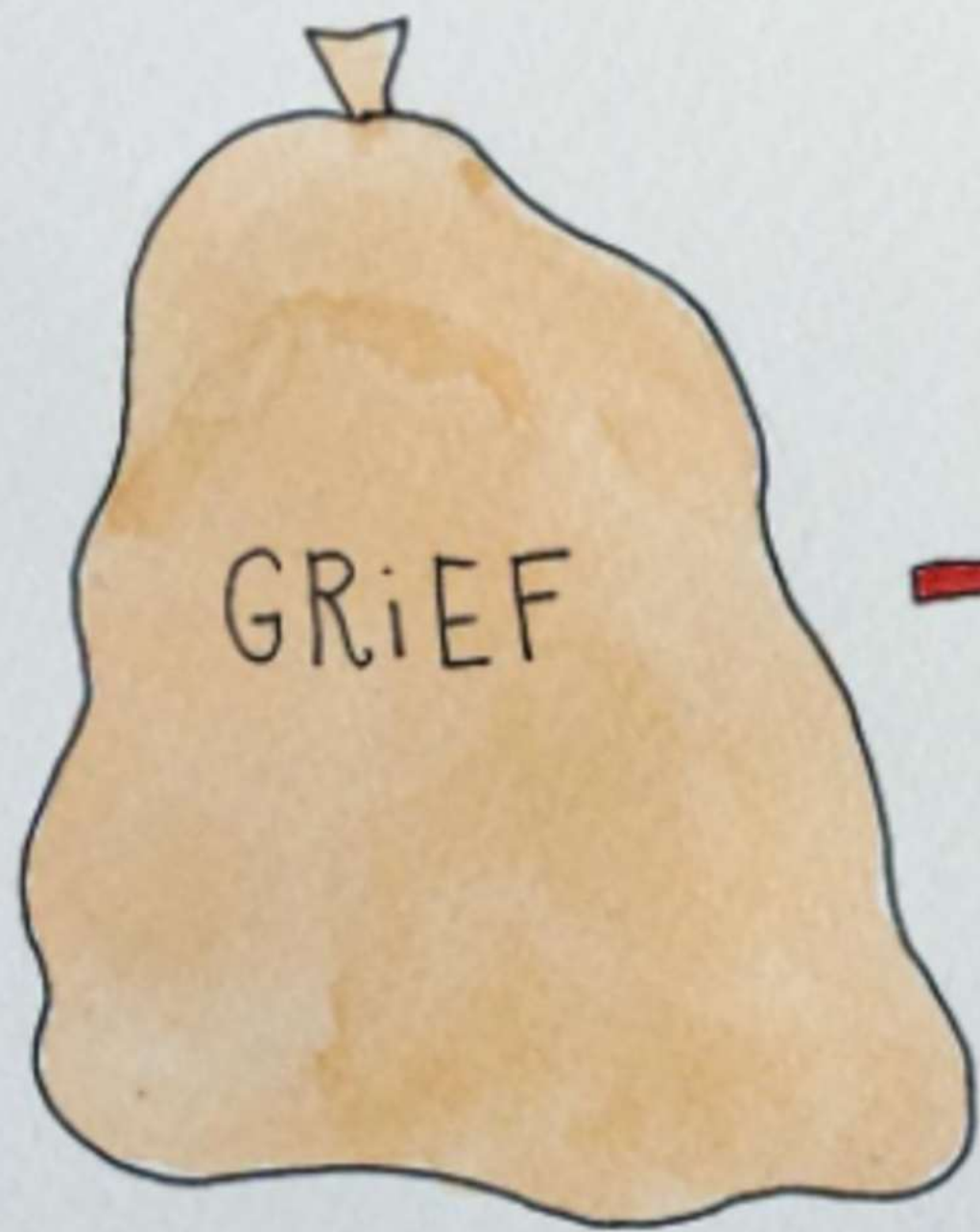
# Grieving is not linear



- 
- 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?





- 
- 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

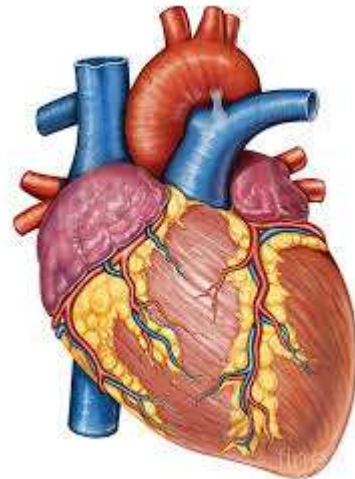
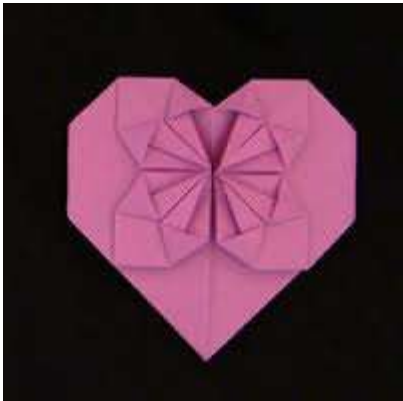
# . BIBLIOTHERAPY



# 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 SUPPORTY 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





A wide-angle photograph of the Chicago skyline at sunset. The sun is low on the left, casting a warm orange glow over the city. The Willis Tower is prominent on the left. The skyline is reflected in the calm water of Lake Michigan in the foreground.

Join Us for  
**HDSA's 32<sup>nd</sup> Annual Convention**  
**Schaumburg, IL**  
**June 22-24, 2017**  
Visit [HDSA.org/convention](http://HDSA.org/convention) for more info



