



# When Negative is not always Positive

Anne Leserman, LCSW  
Assistant Director of Community Services, HDSA



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# Presenter Disclosures

Anne Leserman

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

No relationships to disclose  
or list



Huntington's Disease  
Society of America

# Survivor Guilt- it's a real thing

Seen in war veterans (often associated with PTSD), Holocaust survivors, relatives spared from hereditary illness

Due to:

- Life threatening situation

- Traumatic or catastrophic event

- Illness

# What to watch out for

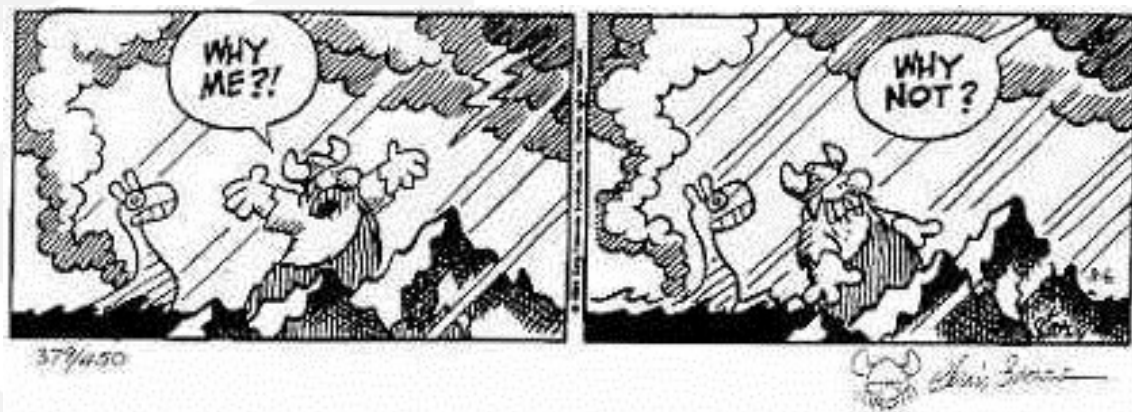
- Spending a lot of time alone
- Comparing yourself with others
- Setting extreme expectations/Am I doing enough?
- Feeling unworthy/ashamed
- Worry that I did something wrong?
- Sleep disturbance
- Emotional numbness
- Extremes of anger and aggression

## How to Cope

- Acknowledge your feelings
- Reach out for support- talk to others that have tested negative that have similar feelings.
- Let yourself mourn
- Take action

# How to find meaning

- Bloom where you're planted
- Treasure the best of each day
- Practice small acts of kindness
- Be around people
- Exercise
- Talk to a mental health professional
- Become an advocate





# HDSA Guidelines-Predictive Testing Process

## **1. Telephone Contact**

## **2. Visit 1**

- Genetic Counseling
- Sign Informed Consent Document
- Mental Health Assessment
- Neurological Exam
- Draw Blood

## **3. Visit 2**

- Disclosure of Results in Person
- Arrange Post-result Follow-up

## **4. Follow-Up**

- Prearranged phone call or in-person visit



# Who Tests?

About 10% of at-risk individuals choose to test.

## REASONS TO TEST:

- Family planning
- Planning for the future
- I have to know

# References

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