



# Defining Yourself and Not the Disease



## Huntington's Disease Society of America

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# 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  
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**Huntington's Disease  
Society of America**

Let's be honest

Having HD in your life is no picnic...

- You might not be able to change the fact that it's a part of your life, but you can learn to live with it and be happy.
- HD has already taken away so much, why let it have the power to take control over your happiness?
- Life's too short to not pursue your dreams, let love in and laugh as often as you can.



*“Find an excuse to laugh every chance you get, especially when you least feel like it .”- Craig Ballantyne*

## What does “defining yourself” mean?

Learn how to enjoy life and not let the disease define who you are, even if it shapes some of your decisions in life.

*“You are not your illness. You have an individual story to tell. You have a name, a history, a personality. Staying yourself is part of the battle.” — Julian Seifter*

When living in a family with HD...

# Allow Yourself to be Happy

Often times people feel guilty being happy when they have loved ones who are sick with HD.

HD has already taken away so much, why let it have the power to take control over your happiness?

You only have one life and your loved ones would want you to live it to the fullest while you can. Pursue your dreams and find what makes you happy.

## Learn to Let Go of Negativity

We unfortunately, have no choice when it comes to having HD in our lives. We can't change what has already happened to us and we have to learn we can't control others.

We need to learn to let go of guilt and anger towards the past.

Accept that the best way to face HD and the things we can't control, is to control how we respond to everything.

Understand that everyone copes with everything differently, and that you can't even compare how you handle things to other is in the HD community. Each one of us is going to handle HD differently. We are each going to have our ups and downs with relationships, testing, taking care of a loved one, symptoms, someone dying etc.

*“We cannot choose our external circumstances,  
but we can always choose how we respond to  
them.”- Epictetus*



# So you found out you have the HD gene – Now What?



## Changing our mindset about HD

We have a responsibility to change the mindset of HD. Rather than saying we are dying from HD, we should have the mindset that we are **living with HD**.

We must not let this disease take away our will to live. Whether we have 20 years, 10 years, 1 year or just tomorrow, we should fill that time with life – friends, family, music, adventure, having special moments and creating memories.

# What are some things we can do?

Make a bucket list



# What are some things we can do?

## Adapt With Symptoms



# What are some things we can do?

Laugh and Enjoy Time with Friends and Family



# What are some things we can do?

## Take a Break



# What are some things we can do?

## Volunteer and Advocate



the happiest  
people i know  
are those who  
lose themselves  
in the service  
of others.  
gordon b. hinckley

