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<u>This PowerPoint was Compiled for SC Huntington's</u> <u>Disease Affiliate's and Center of Excellence's Online</u> <u>Support Group using multiple resources including the</u> <u>Mayo Clinic, and Harvard Health</u>

# **OBJECTIVES**

#### **Unpack Key Terms**

- Loss
- Grief
- Impact

#### Discuss Tips for Coping



## WHAT IS LOSS?

The FACT or PROCESS of losing something or someone

- Loss of a physical and/or cognitive ability
- Losing independence (loss of home)
- Illness/loss of health
- Loss of roles within the family
- Loss of financial security
- Serious illness of a loved one
- Relationship breakup
- Death of a pet
- Change of job
- Move to a new home
- Graduation from school
- Loss of a close friend
- Death of a partner, family member, friend, colleague





## AMBIGUOUS LOSS

• Ambiguous loss is the confusing feeling of interacting with someone who is not fully present mentally or socially, as often happens to family caregivers who are closely involved with a person living with dementia or in this case, Huntington's Disease

## WHAT IS GRIEF?

A natural reaction to YOUR loss (losing someone or something that's important to you)

Experiencing a feeling of deep sorrow on one end of the continuum to trouble or annoyance on the other

Individual experiences of grief vary and are influenced by the nature of the loss

Mourning can last for months or years



### ANTICIPATORY GRIEF

 Anticipatory grief is the emotional pain and sadness that arises in advance of an expectant loss or death."



#### **Kübler-Ross Grief Cycle**

Denial Avoidance Confusion Elation Shock Fear

Anger Frustration Irritation Anxiety

Bargaining Struggling to find meaning Reaching out to others Telling one's story Acceptance Exploring options New plan in place

Moving on

Depression Overwhelmed Helplessness Hostility Flight

Information and Communication Emotional Support

Guidance and Direction



## IMPACT OF GRIEVING A LOSS

- Must accept YOU can't control the process and must prepare for varying stages of grief
- Feel lethargic; Overall lack of energy
- May have a desire to sleep too much or experience insomnia
- May not experience the same pleasure from interacting with others and withdraw socially
- May have crying episodes, etc.
- If prone to depression or anxiety, may exacerbate those symptoms.



## GRIEF AND LOSS SIGNIFICANTLY IMPACTS FAMILY FUNCTIONING

- Loss can mimic the feel of a roller coaster, you may feel fine one moment but then 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,
- Family dynamics may feel constrained because roles may change, limiting forward movement



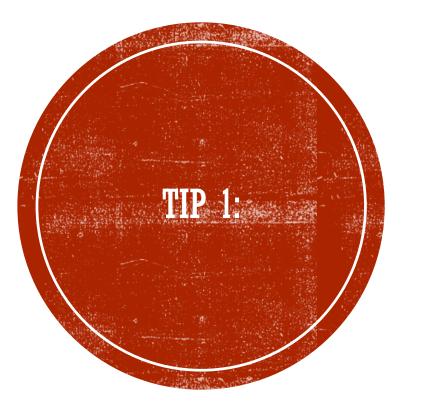


## **IMPACT ON CAREGIVER**

Depending on your situation, impact can manifest in several different ways

- Studies consistently report higher levels of depressive symptoms and mental health problems among caregivers than among their noncaregiving peers.
- Increased anxiety and frustration
- Some 16% of caregivers feel emotionally strained and 26% say taking care of the care recipient is hard on them emotionally. An additional 13% of caregivers feel frustrated with the lack of progress made with the care recipient.
- Caregivers have an increased risk of heart disease.
- Caregivers have lower levels of self-care.
- Increased lack of energy
- Withdrawal socially and from activities

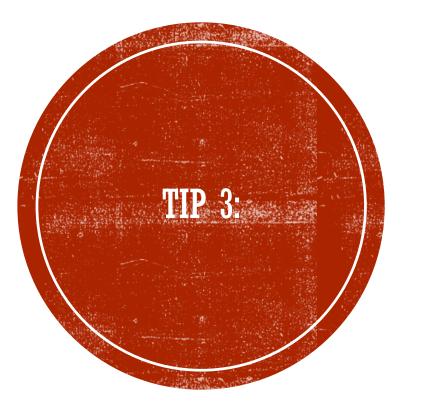




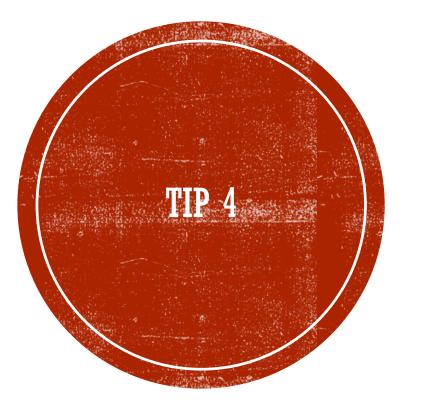
## Acknowledge the grief and pain of the loss.



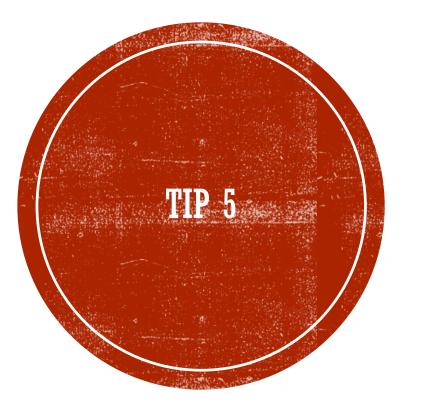
## Remember that the present doesn't override the past.



## Understand that the illness isn't the person.



#### Accept comfort and support from others.



### Develop A Self-Care Plan

### WHAT THINGS CAN YOU DO?

