

# Communicating with Youth about HD

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Open communication is essential for healthy relationships, growth, understanding and knowledge. Communication can be verbal, written and non-verbal through emotions, reactions, facial expressions and behavior. Outlined below is information about engaging in discussion and on-going communication with your children about the Huntington's Disease diagnosis in the family. Good communication with your children can assist all members of the family in coping and dealing with the changes and loss that will occur over time. Allowing children to discuss HD will prepare children to best cope with the changes and losses that may lie ahead. As the children age their cognitive skills will develop and they will be able to better understand the information being discussed.

## Who, How, When & the Why on talking to kids?

### WHO

- It is important to make sure the child is familiar and comfortable with the person who is sharing information
- The person must be knowledgeable and have correct information about HD
- IF the HD person can participate, they should
- Other persons can include, non-HD parent, close family member, close friend, or professional healthcare provider

### HOW

- Environment should be comfortable, familiar and safe with minimal distraction, so you and the child are free to express your feelings honestly.
- Understand that the initial conversations may be uncomfortable for you and the children and will likely get easier as the foundation for open communication is established.
- Remember that you will need to talk to different age children separately as they will have different questions, concerns and reactions.
- Be present and prepared to spend the necessary time to needed to address any questions or feelings.

### WHEN

- Children should be told at all ages as close to initial diagnosis as possible.
- The earlier you talk about HD the more normal and comfortable it will be for you and the child.
- It is never too early to tell the children
- there is never a "right time".

### WHY

- Children are great observers and can often sense when something has happened through your facial expressions, behavior and emotions.
- If children need answers and don't feel they can get them from family, they will get them from outside sources and risk getting incorrect information.
- Remember, it takes a lot of energy to "hide the truth."
- Fear is learned
- By not discussing the diagnosis children will learn to fear HD and potentially the person with HD.

## Keys to the discussion

### Honest & Genuine

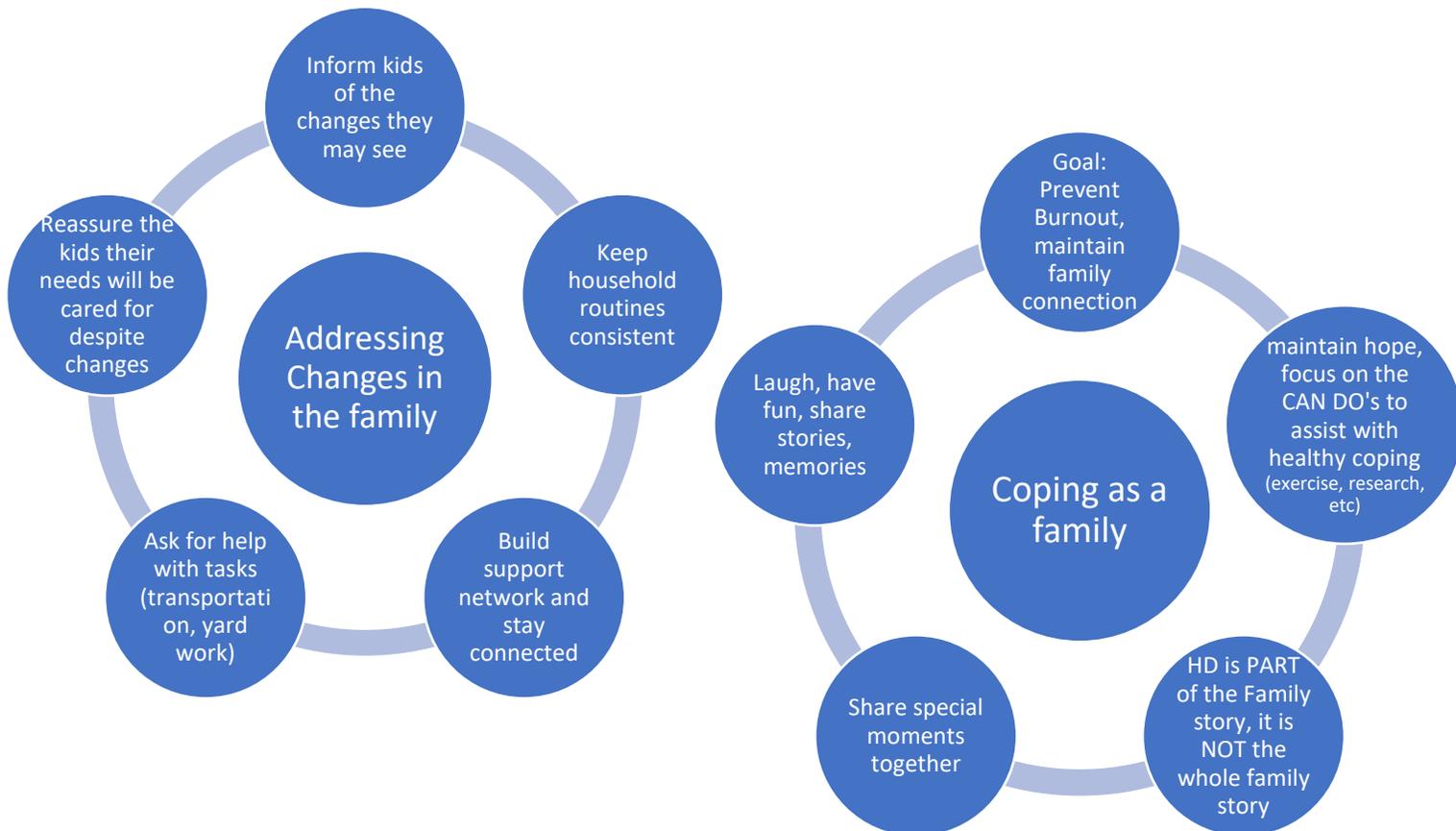
- Children need to know you will ALWAYS tell them the truth
- They will likely pay more attention to your emotions and actions more than the words.
- Demonstrate there is no shame or secrecy in discussing HD or their feelings
- Share your feelings, fears or concerns with them (age appropriate of course)
- Only make promises you can keep

### Information Sharing

- Share age appropriate information using words they understand
- Be comfortable saying "I don't know", "HD is confusing, complex and sometimes difficult to understand" so "let's find out the answer together"
- Assure them that you will share information as you get it.
- Provide space and offer to discuss whatever they need in the future
- Don't assume children are too young for information, if they ask find an age appropriate way to discuss

### Active Listening/Allow for Silence

- Let child direct the conversation as they will ASK what they need to know.
- Respect what the child has to say
- address all their questions
- acknowledge their feelings
- give time to process the information and feelings
- may need to schedule a follow up conversation



## Different Ages and Stages

<p style="text-align: center;">Age 0-2 (Babies &amp; Toddlers)</p>	<p style="text-align: center;">Ages 2-5 (Preschoolers)</p>	<p style="text-align: center;">Ages 5-12 (School Age)</p>	<p style="text-align: center;">Ages 13-17 (Teenagers)</p>
<p>Children at this age sense your feelings and react to your emotional state.</p> <ul style="list-style-type: none"> <li>behavior, appetite and sleep may change, and developmental milestones may be delayed due to feeling anxious or depressed.</li> </ul> <p>Interact with:</p> <ul style="list-style-type: none"> <li>soothing voice</li> <li>hugs and affection</li> <li>patience</li> </ul> <p>Intense discussions or arguments should not take place in front of children this age.</p> <ul style="list-style-type: none"> <li>They will not understand what is being said but will definitely react to how you are feeling.</li> </ul>	<p>Tell them small bits of information, define the illness</p> <ul style="list-style-type: none"> <li>Mom/Dad has an illness called Huntington’s Disease.</li> </ul> <p>Allow them to ask questions if they have them, answer with simple, brief explanations.</p> <p>Children of this age may experience:</p> <ul style="list-style-type: none"> <li>anxiety</li> <li>changes in behavior, sleeping (nightmares) or attachment fears when leaving caregiver</li> <li>feelings received from non-verbal communication</li> </ul> <p>Keep routines as consistent as possible.</p>	<p>Can be overly concerned about health</p> <ul style="list-style-type: none"> <li>Do not overwhelm with details of appointments as they may worry about them to the point they may become ill.                             <ul style="list-style-type: none"> <li>Share outcome of MD appoints “I had an appointment today and the MD says I’m doing well!”</li> </ul> </li> </ul> <p>Let the school/teachers know what is happening</p> <ul style="list-style-type: none"> <li>They can be part of the child’s support while not with the family.</li> </ul> <p>Children of this age may experience changes in:</p> <ul style="list-style-type: none"> <li>Eating</li> <li>Sleeping (nightmares)</li> <li>Anxiety about leaving caregivers, going to school</li> <li>changes in school performance</li> <li>Social withdrawal, changes in friendships</li> <li>Regression to bed wetting, sucking thumb, etc.</li> </ul> <p>Provide children with attention and affection.</p>	<p>Children of this age are prone to mood swings, anxiety and depression (w/out presence of illness in family) and this may increase with the HD information.</p> <p>Confusion between wanting to be independent, yet still dependent on adults.</p> <ul style="list-style-type: none"> <li>Not sure how to handle their own emotions.</li> </ul> <p>Teens may express anger and withdraw when HD is discussed.</p> <p>AND</p> <p>Teens may seek support from outside family (peers, teachers, etc.)</p> <p>Assure them any feelings they are having are natural, normal responses.</p>

<p>Age 0-2 (Babies &amp; Toddlers)</p>	<p>Ages 2-5 (Preschoolers)</p> <p>If they know what to expect they are better prepared to cope.</p> <ul style="list-style-type: none"> <li>Function on day-to-day basis: tell children the schedule for the day.</li> </ul> <p>Reassure them nothing they have done has caused HD or can change the situation.</p> <ul style="list-style-type: none"> <li>Children at 4-5 may feel they have “magical” powers and if they wish for something (good or bad) it will come true.</li> </ul>	<p>Ages 5-12 (School Age)</p> <p>They will need to feel included and aware of family situation/changes.</p>	<p>Ages 13-17 (Teenagers)</p> <p>Provide information, allow them to ask questions and express their feelings when they are ready.</p> <ul style="list-style-type: none"> <li>Provide written materials to support the information you are discussing.</li> </ul>
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## Discipline



**Feelings and Emotions:** If you are showing how you feel, children will feel more comfortable expressing their feelings. If children do not learn to express themselves, they may become frightened of their strong emotions instead of accepting them. Children of all ages may experience:

 <p>Denial, Shame, Sadness, Depression , Anxiety</p>	 <p>May use humor or jokes to mask feelings</p>	 <p>Grief/Loss</p> <ul style="list-style-type: none"><li>• Loss of parent/role model</li><li>• Loss of family opportunities</li><li>• Loss of secure future</li><li>• Loss of control</li></ul>	 <p>Anger with sick parent</p>	 <p>Need to be "perfect kid"</p> <p>feels guilt, sadness or anger towards themselves for not being "perfect"</p>
 <p>Feel sorry for themselves</p>	 <p>Overly attached or fearful about leave ill parent</p>	 <p>Withdrawn</p> <ul style="list-style-type: none"><li>• pulling away so they can be independent in case something happens</li></ul>	 <p>resentment or confusion about role in family and caring for parent</p>	 <p>Act out, act sick to get attention or stay home with ill parent*</p>

\*Anxiety and stress can be experienced in physical ways such as headaches, stomach aches, etc. and should be addressed if experienced over a prolonged period

## NOT ALL IS BAD....

When faced with a challenging, life threatening illness like HD it is possible for children to grow in their ability to:

- Understand and accept another person, despite differences
- become more self confident and independent
- May learn to be more responsible and sensitive to others needs
- experience optimism and hope
- DO NOT UNDERESTIMATE and Child's ability to teach you how to adapt, cope and be positive in hard times.

## References and Resources

**Books/Videos**  
search internet for:

- Talking to Kids about HD
- Talking to Children about Death
- Kids coping with grief, loss, medical information
- Hospice agencies usually have good publications about difficult conversations with children about loss, death, health , etc.

**Support Groups or Education Events**  
talking with other HD families about their experience

**Huntington's Disease Youth Organization (HDYO)**

**HDSA National Youth Alliance**

**HD Social Worker or HD Team**