



Communicating with Children about HD

Lisa Kjer-Mooney, LCSW

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.

Reasons for Talking with Kids about HD

- 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 be scared of HD and potentially the person with HD.

Who Should Tell the Kids?

- Ideally the person with HD should discuss the diagnosis so the children feel free to talk to them about any future questions or feelings.
- Other persons can include:
 - Spouse
 - Close family member
 - Close friend
 - Professional healthcare provider
- 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.

When Should I Tell the Kids?

- 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 and there is never a “right time”.

How Should I Tell the Kids?

- Discussing HD with your children will be based on your own experience of how you were told.
- Examine and address your own feelings and concerns about the situation prior to talking with the children.
- 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.

What Should I Tell the Kids?

- Be honest and genuine
 - If children don't believe you they will not feel comfortable asking for more information or sharing their feelings.
 - Remember they are great observers, they are going to be watching you more than they are listening to the words.
 - Demonstrate there is no secrecy or shame in discussing HD or their feelings.
 - Share your feelings, fears or concerns with children (age appropriate, of course!)
- Share age appropriate information they will understand.
- Actively listen
 - Respect what children have to say.
 - Address all their questions.
 - Acknowledge their feelings.
- Have the child direct the conversation.
 - They will ask what they want to know.
- Be comfortable saying “I don't know”.
 - Admit that HD is confusing and difficult to understand.
 - Let them know that you are doing your best to find out as much information as possible and you will share what you know.
- Only make promises you can keep.
- Give the child time to process the information and his/her feelings.
 - Some children may not want to talk during this initial conversation.

- Provide them space and offer to discuss with them in the future if they would like.
- Avoid making comments that they are too young for this information.
- Keep information simple and brief.

Addressing Changes in the Family

- It's important to let children know that gradually, there will be changes with both the person with HD and the family.
- When possible try to keep household routines consistent.
- Build a support network and stay connected.
 - Neighbors, school, church, health care providers, HD support groups
- Ask for help from other family, friends, and neighbors to assist as needed.
 - Transportation
 - Child care
- Reassure the children that they will continue to be cared for and have their needs met.

Different Ages and Stages

Age 0-2 (Babies & Toddlers)

- These children will sense your feelings and react to your emotional state.
 - Their behavior, appetite and sleep may change and developmental milestones may be delayed due to feeling anxious or depressed.
- During this age you should interact with:
 - soothing voice
 - hugs and affection
 - patience
- Intense discussions or arguments should not take place in front of children this age.
 - They will not understand what is being said, but will definitely react to how you are feeling.

Ages 2-5 (Preschoolers)

- Tell them small bits of information, define the illness
 - Mom/Dad has an illness called Huntington's Disease.
- Allow them to ask questions if they have them, answer with simple, brief explanations.
- Children of this age may experience:
 - anxiety
 - changes in behavior, sleeping (nightmares) or attachment fears when leaving caregiver
 - feelings received from non verbal communication
- Keep routines as consistent as possible.
- If they know what to expect they are better prepared to cope.
 - Function on day-to-day basis: tell children the schedule for the day.
- Reassure them nothing they have done has caused HD or can change the situation.

- Children at 4-5 may feel they have “magical” powers and if they wish for something (good or bad) it will come true.

Ages 5-12 (School Age)

- Can be overly concerned about health
 - Do not overwhelm with details of appointments as they may worry about them to the point they may become ill.
 - Share outcome of MD appoints
 - I had an appointment today and the MD says I’m doing well!
- Let the school/teachers know what is happening
 - They can be part of the child’s support while not with the family.
- Children of this age may experience changes in:
 - Eating
 - Sleeping (nightmares)
 - Anxiety about leaving caregivers, going to school
 - changes in school performance
 - Social withdrawal, changes in friendships
 - Regression to bed wetting, sucking thumb, etc.
- Provide children with attention and affection.
- They will need to feel included and aware of family situation/changes.

Ages 13-17 (Teenagers)

- 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.
- Confusion between wanting to be independent, yet still dependent on adults.
 - Not sure how to handle their own emotions.
- Teens may express anger and withdraw when HD is discussed.
- Assure them any feelings they are having are natural, normal responses.
- Provide information, allow them to ask questions/express their feelings when they are ready.
 - Provide written materials to support the information you are discussing.
- Teens may seek support from outside family (peers, teachers, etc.)

Children’s 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:
 - Denial
 - Shame
 - Grief:
 - Loss of a parent/role model
 - Loss of family opportunities

- Loss of secure future
- Loss of control
- Feeling sorry for themselves
- Angry with sick parent
- Needing to compensate and be the “perfect kid” and set unrealistic goals for themselves
- Guilty for feeling sorry, angry or not being “perfect”
- Overly attached or fearful about leaving sick parent
- Withdrawn (pulling away so they can be independent in case something happens)
- Resentment towards having to care for sick parent
 - confused about their role in family
- May act out, act sick to get attention or stay home with sick parent
 - Remember, 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.
- May use humor or jokes to cover up feelings

Discipline

- It is normal to see some acting out when there is a crisis in a family.
- Communicate and talk to children about what behavior you are seeing.
 - Show love and affection
 - Set limits on negative behavior
 - Enforce rules and consequences
 - Remain consistent with routines
 - Reward positive behavior
 - Verbalize appreciation for their help or accomplishments

Coping as a Family

Goal: To prevent burn out, take care of yourself and continue to have fun as family.

- Convey positive information
 - Having a sense of hope will assist with healthy coping.
 - HD should NOT be the center of family life.
- Continue to share special moments together as a family.
- Laugh together
- Have fun
- Share stories, memories
- Participate in family activities

Children's Growth

- Children need to know and understand their whole history in order to have a sense of pride and belonging.
- When faced with a challenging, life threatening illness like HD in the family 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 become more responsible as well as sensitive to others needs.
 - Experience optimism and hope.

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. As stated before, open, honest and on-going communication about HD and their feelings will assist with coping and establishing trust in the family.

References and Resources

- "Talking to Kids About Huntington's Disease"; Bonnie L. Henning, LCSW; www.talkingtokidsabouthd.com
- "Talking to Children about Death"; www.hospicenet.org
- "Kids Can Cope: An Activity Book From Children For Children Who Are Living with Change and Loss", Emilio Parga, MA
- 2010 HDSA National Convention, Talking with Kids About HD: Panel Discussion with Parents and Children.
- Huntington's Disease Youth Organization, www.hdyo.org
- Huntington's Disease Society of America, www.hdsa.org