

## Learning about HD – a Child’s Response

Just as the symptoms of HD vary from one individual to another, families’ adjustment to the disease and their abilities to cope vary. However, there are some common emotional reactions that children may experience when they are faced with a parent who has HD.

Children may go through a grieving process over the changes that HD brings into his life. Grief is a normal emotional reaction to a significant loss. Having HD results in many significant losses both for the person who has the disease and for all other members of the family.

Grieving the losses brought about because of HD is not a one-time thing. Children may have lost their involvement with a physically active parent. They may have lost the opportunity to have a carefree childhood, free from the worries that having an ill parent brings. They may have lost free time because of having to take on more responsibilities.

The feelings and reactions that are part of the grieving process may recur again and again. They may recur each time the disease progresses and there is one more thing the person with HD can no longer do. Here are some possible reactions:

### **Shock**

- Some children may be very surprised or shocked to learn that Mom or Dad has HD, especially if they have not noticed any apparent symptoms (e.g. mom doesn’t look sick).
- This may lead to the child becoming frightened or worried. These are perfectly normal reactions.

### **Denial**

- Shock is often followed by denial.
- Children may pretend that nothing has really happened. Some children do not ask questions simply because they want to forget about HD (if they don’t mention it and ignore it the disease will go away)
- Denial may allow them some time to absorb the news and get over the initial shock without having to deal with painful emotions.

### **Anger & Frustration**

- Anger may follow and be directed, not only at the parent who has HD, but also at everyone else, and usually for not meeting the child’s needs
- Anger may be the most difficult feeling to deal with. It is a very natural feeling. It’s a feeling that comes when we feel confused, hurt, scared or frustrated. It is very normal. It is not wrong to feel anger but sometimes children express their anger in inappropriate ways.
- Anger and resentment are very common in families affected by a chronic illness. Cancelled activities, reduced income, loss of one or both parent’s attention because of the focus on HD, can all contribute to a child’s feeling anger and frustration.
- Their anger is a reaction to the disease and what it has changed for them.

### **Sadness**

- After expressing anger, children may feel sad and guilty.
- They would like to see the disease go away and have their parent back as they were before.
- They may feel guilty about getting angry and some may imagine that they are responsible for the disease or certain symptoms.
- Sometimes the sadness feels overwhelming, as though it will never end although it usually does diminish. When it does not there is potential for the sadness to turn into depression. Children may be very withdrawn and isolated. Restricted relationships with friends and social activities can add to the isolation. If depression occurs some outside help may be needed.

Children who grow up in a home where there is HD face several challenges. They may be assisting with the care of the person who has HD. They may be required to take on certain household responsibilities that are usually reserved for adults. Their free time may be limited and their social life disrupted.

Remember that every child is unique and may react differently. A brother and sister, depending on their age and personality, may react very differently. Try to be attentive to the personal needs of each child. Being aware of and understanding your child's emotional response is the first step to helping your child cope.

*Taken from "Reaction to Huntington Disease: Focus on the Child", a handout prepared by Sandra Funk, MB Resource Centre, for a conference presentation, 2003*

### **Fear for the Future**

- Most children are afraid of losing their parent with HD.
- Adolescents sometimes think that they will have to stay home to look after mom or dad when the disease gets worse.
- They may experience doubts about their own future because of their genetic risk.

### **Anxiety**

- Children may worry about their parent, their family & themselves. Some worry about their parents' feelings.

### **Embarrassment**

- At having a parent who looks or acts different
- They may avoid bringing friends home, and they may not want their parent going to their school or to activities.