

## **Suggestions to Help Children Cope**

Children who live with Huntington disease face challenges that most children their age do not. But HD does not have to take over a young person's life. Families must try to deal with each day and each situation as it comes. Here are some suggestions to help parents help their children cope.

### **Ensure that your child's needs are being met.**

- This includes basic needs such as food, shelter, clothing and love, but it also includes the need for friends, fun and attention.
- Reassure your child that his/her needs are as important as those of the family member with HD.

### **Provide your child with knowledge about HD**

- It is important for children to know about HD and how it is going to affect their parent & themselves.
- Encourage your child to ask questions at any time.

### **Reassure your children**

- Frequently reassure them of your love and that they will always be cared for.

### **Ensure your child has an emotional outlet**

- It is important that each child has someone they can talk to about their feelings. It doesn't matter whether this person is a parent, friend, teacher, or another child who is at risk.
- Anyone who can listen will do - they don't have to come up with the answers.
- Talking to a pet or a stuffed animal or doll can help.
- Painting a picture to express

their feelings or writing about them can help

- Corresponding with an email or pen pal whose parent also has HD might be beneficial.
- The important thing is to get the feelings out and to remind children that their feelings are normal, not bad or crazy.
- Sharing your problems and concerns is a good first step to overcoming them. Many people feel better knowing that they are not alone in having to face HD.

### **Make sure your child has free time**

- Make sure your child has time to be with friends.
- A child who lives with HD daily could benefit from a break. This could be a family holiday without the affected person or it could be a week at summer camp.

### **Make certain that you are not imposing too much responsibility on your child**

- If you are unable to cope on your own, seek out the support services that are available in the community, such as home care, respite, etc.

### **Set firm, clear limits and follow through effectively**

- There may be a tendency for parents not to push kids because they feel enough has been asked of them already.
- All children need clear limits and consistent discipline.

### **Encourage positive social interaction between your child & the parent with HD**

- Arrange fun outings or activities together if possible
- Quiet time at home can be just as positive, this could involve

- looking at family pictures, bedtime stories, or cuddling on the sofa while watching TV
- These activities will maintain a positive relationship and foster happy memories

**Encourage children to develop relationships with other adults**

- Especially, if the parent with HD is in the advanced stages
- Encourage children to become involved with other adults, such as a friend's parent, an aunt or uncle, a "Big Sister or Big Brother".
- This will provide them with an additional adult role model. It will also give them the opportunity for more activities and fun.

**Provide your children with information about resources that can help during a crisis**

- A resource that children may find helpful is the Kids Help Phone: 1-800-668-6868. This is a toll-free, bilingual telephone counselling service for children and youth. They provide emotional support, counselling, information and referral.
- Your local HD Resource Centre or IFS Worker can provide information and support.

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