

## Hemophilia and Relationships: Making It Work

*Chronic illnesses can often impact the entire family in a profound way. In many ways, the condition is an opportunity to make the family a stronger unit. It is important to notice the impact that Hemophilia is having on your family. In managing its impact, communication becomes key.*



- ▶ **Talk to your children about their hemophilia.** Most children understand a good deal about their illness and can help manage it when given the chance to voice their feelings and opinions.
- ▶ **Do not ignore or neglect the healthy siblings.** Sometimes families get so focused on the illness that the healthy children can feel left out.
- ▶ **Work Collaboratively with your Healthcare Providers.** This means educating yourself and becoming your child's advocate. It also means being assertive, but not aggressive. Alienating the doctors or nurses will not help your child. Your home healthcare company can be a strong support.
- ▶ **Hemophilia can affect the relationships within the family and change the normal patterns of interacting.** Family members must provide more than physical support of the individual. Hemophilia affects the emotional, spiritual and social aspects of a person's life as well.
- ▶ **Be aware and educated.** Adolescents with Hemophilia have a lower self esteem compared to teens without it. Depressive and anxiety symptoms are more frequent in children and adolescents with hemophilia.
- ▶ **Ensure that Hemophilia is put in its proper place.** It doesn't define who you are as a family. It is only one aspect of your lives.
- ▶ **The biggest problem in marriage and families with a chronic illness can be the different styles of coping.** For example, one person may be in denial, while the other is accepting.
- ▶ **A family that has incorrect or inadequate information may have a harder time adjusting to the diagnosis.**
- ▶ **Family members must adjust their expectations for each other while learning to cope.**
- ▶ **Families under stress will repeat patterns of behavior even if they are ineffective or negative.** The time to change these patterns is not in the midst of crisis.
- ▶ **The biggest influence on coping is the family's perception of the illness.**
- ▶ **There are higher divorce rates in families with Hemophilia.** This means we have to work twice as hard to work on coping and communication.
- ▶ **Strong families are not families without problems.** They are simply families who face the challenges together and support one another in the crisis.
- ▶ **Strong families have learned to be flexible and adapt to what life throws their way.**
- ▶ **Strong families have these things in common: Commitment, Appreciation and Affection, Positive Communication, Spiritual Well being, and the ability to cope with stress.**

*Do not be afraid to reach out to others for support! The strongest relationships are developed when people take advantage of the resources available and educate themselves.*

*To learn more, contact your BioRx representative or call us at: 866-442-4679*