



## Impact on the Family/Siblings

**The most important thing families can do to maintain balance is to make sure that hemophilia does not become or define the family**

### *Achieving balance*

1. Involvement in hemophilia organizations can be helpful, BUT over involvement may not be good for the family as a whole, particularly other children
2. The family needs to communicate openly and share concerns that you all have
3. A positive atmosphere will go a long way in maintaining family balance
4. Some family members may feel the need to talk and share often, while others may be more private and introspective. Regardless of how someone copes, his or her feelings must be respected
5. Parents must recognize and acknowledge the needs of all children in the family, not just the child with hemophilia

### *Siblings*

1. Involvement in hemophilia organizations can be helpful, BUT over involvement may not be good for the family as a whole, particularly other children
2. The family needs to communicate openly and share concerns that you all have
3. A positive atmosphere will go a long way in maintaining family balance
4. Some family members may feel the need to talk and share often, while others may be more private and introspective. Regardless of how someone copes, his or her feelings must be
5. Provide age-appropriate hemophilia education to your nonaffected children
6. Provide age-appropriate education to daughters regarding carrier risk and testing
7. Do not make siblings feel left out, unimportant, or unnoticed
8. Remind siblings that they did not cause hemophilia—even if they accidentally cause a bleed
9. Reinforce that siblings are important—do not allow them to minimize their own needs or act out to get attention
10. Remind your children:
  - No one is to blame for bleeds
  - The caregiver will handle treatment
  - To participate in activities that are of particular interest to them
11. Encourage all family members to have a life away from hemophilia

