July 18, 2011: Living with Asthma: Family and Close Relationships

Participants in this month’s Asthma Institute Support Group shared the particular challenges of managing their illness while maintaining close relationships with spouses, parents, and other family members. Participants described disappointments of not being able to attend their children’s special events, or even attend a family funeral because of bad weather. One participant has been unable to work, and unable to contribute financially to the family as she had before. For another participant, her adult-onset asthma has completely altered the way she spends time with her husband; formerly physically active as a couple, she often cannot join him in the activities they both enjoy.

Several participants described feeling an internal pressure to act as if they are in good health, to hide the strain and symptoms of illness. They feel pressure to keep up with people and activities around them and, significantly, to prevent their families from worrying about them.

Participants described not wanting to disrupt family members’ lives and routines by involving them in asthma-related medical needs (appointments, hospital visits). Some participants described family members who just “Don’t get it,” meaning they do not understand the nature of their asthma and treatment needs, even to the point of questioning the legitimacy of their illness. Others have family who are quite knowledgeable and understanding, and yet they still prefer to hide their struggles with illness. Why?

One participant stated, “I worry enough for the both of us!” And others agreed that once family members become alarmed, family life can become overwhelmed with too much worry. As a result, folks described keeping feelings to themselves and pushing themselves to the limit physically. The downside of this, however, is that as stress and fatigue increase, so does the risk of exacerbation. We discussed the tradeoff of hiding feelings and symptoms vs. reaching out to others for support and keeping loved ones informed when one is struggling. But it was difficult for some participants to think of altering their ways of coping—as it often is. Others cited the importance of having a support group such as this or some contact with others who have a deep understanding of how it feels to live with severe asthma.

We hope that this group will be a forum to continue to address issues related to living with asthma. We hope participants will come to use it as a resource for sharing their experiences and suggestions, to keep from feeling too alone with their illness, and to explore new ways of coping.