

Families Coping with Autoimmune Disease

by Robert H. Phillips, Ph.D.

An autoimmune disease can certainly have an impact on the family. It not only affects the individual with the condition; it also can affect every member of the family. The way the family feels about how it affects a loved one, and the cohesiveness of the family, is very important. If family members get along well, and they, like the person with the autoimmune disease, cope successfully with the disease, this will provide an important, solid springboard for progress.

Family members may experience many of the emotional reactions that the person with an autoimmune disease does--ranging from anger and depression to fear of the future or fear of complications. Sometimes family members react more strongly and possibly even more irrationally than the person who's been diagnosed with the autoimmune disease. There may be more denial on the part of a family member. There may be guilt, especially on the part of parents if they feel that they have somehow contributed to the onset of the autoimmune disease in their children.

Some family members ignore or play down the disease. They often do so because they can't deal with it. They may be afraid of its getting worse. They may feel that they're unable to provide the practical or emotional support needed. Or they may be unable to accept the possibility that it might have something to do with them. Ignoring or denying it may help them not to think about it, hoping that it will go away.

On the other hand, there are family members who think of nothing else besides the autoimmune disease. They may constantly bombard their loved one with questions about their symptoms, treatment, and other activities. They may feel responsible for the person and believe that they must take total care of their loved one. They may dwell on this to the extent that they may appear to be smothering to the person.

Family members should use many of the coping strategies that the person with the autoimmune disease uses to deal with the condition. For example, education, support groups, and coping strategies are valuable for all. Let's discuss some specific suggestions for ways that family members can improve their ability to cope with an autoimmune disease.

Have a family powwow. Since all family members are affected if someone in the family is ill, it can be very helpful for them to be able to share how they feel. A family meeting and discussion can help you improve constructive communication within the family. For this technique to work best, all available family members should be included. Give each person a predetermined amount of time (start with five minutes) to share feelings, gripe, air grievances--even cry. However, the intent of any communication must be constructive. No one else should interrupt. Reactions are permissible, but only after each person has had his or her few minutes. Just getting together to discuss feelings can bring family members closer together.

Strive for good communication. There are a number of things you can do to maximize the effectiveness of communication between family members. The better the communication, the closer the family, and the more support will be provided from all to all. Consider the following suggestions:

- Be cautious and gentle in any feelings that are expressed.
- Schedule time for conversations related to the autoimmune disease and its effect on each member of the family.
- Allow others time to think about the issues that need to be discussed.
- Allow a reasonable but not overwhelming period of time for discussion.
- Express feelings in a clear, objective way. Avoid threatening language.
- Ask clarifying questions (in a positive, constructive way) if there are any points that are not understood.

Listen carefully. Listening is one of the most important parts of communication. If you don't really hear what others are saying, how can you truly understand what they're feeling? Some suggestions include not interrupting when people are expressing their feelings or opinions, making eye contact and being sure you're fully aware of what they're saying, and even restating their comment in your own words to show that you understand what they've just said. Being a good listener will also set a good example for others--it will show them that you would like them to listen to you, too.

Look through the other person's eyes. When you want to communicate effectively, it is extremely helpful (if not necessary!) to view the problem through the eyes of the person you're talking to. If you're totally wrapped up in your own point of view, you'll have a much more difficult time trying to understand anyone else's feelings or comments. But if you try to see the situation through the other person's eyes, it will help you when you try to explain your point of view.

Work together to change family responsibilities. An autoimmune disease can cause a shift in responsibilities for different family members. Different family members may have to pick up any slack this creates. Changes in responsibilities can bring about anger or resentment. So work together with your family. Discuss these difficulties constructively.

Encourage family events. Often, family cohesiveness is strained because of a lack of time spent together doing enjoyable things. This can be changed! Have each family member suggest the pleasurable activities they enjoy. Try to get a consensus, considering any limitations the autoimmune disease may impose, and schedule an activity at a time convenient to all. Remember: The family that plays together stays together!

Consider implementing additional helpful tips. There are many additional ways of providing loving support for someone with an autoimmune disease:

- Show a willingness to participate in any changes necessitated because of the autoimmune disease. Examples include participating in exercise programs or special activities, eating healthier, and being a willing participant in nutritional modifications.
- Try to minimize the degree to which you are critical of your loved one for inappropriate behaviors.

- Be supportive of your loved one if he or she is going through an especially hard time. Being able to provide genuine, loving support is one of the greatest gifts you can give to your loved one. And don't always feel that you have to come up with answers. Just being supportive and empathetic can be helpful enough.
- Try to be extra tolerant and supportive, rather than being critical, during times when your loved one's symptoms (physical or emotional) are more pronounced. It's also important to be aware of the difference between medical reasons or non-medical reasons for these changes.
- Use humor as an important coping strategy, but make sure that this is not perceived as making fun of the person with the autoimmune disease.

A united family is one of the most important ingredients in successful coping. Having an autoimmune disease makes family relationships more vulnerable to problems, arguments, and even crises. Working through disease-related problems requires much more attention to the feelings of each family member. But it's worth it. If problem spots can be smoothed out, a cohesive family can really be an asset in successfully coping with an autoimmune disease.

About Robert H. Phillips, Ph.D.

Dr. Robert H. Phillips is the founder and director of the Long Island, NY, Center for Coping (www.coping.com), a multiservice organization that specializes in helping individuals and families improve their ability to cope with medical illnesses, stress, family concerns, and other life problems. Dr. Phillips is a charter member of AARDA's Scientific Advisory Board and serves on its Board of Directors.

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