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Living with a Rare Disorder – II

What do you need to know about your illness? (Part 2 of a 3-part series)

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In a previous issue of *Orphan Disease Update*, I wrote about self-pity and self-blame, and about guilt and shame as feelings you don't have to live with. In this issue, I'll write about the feeling of hurt which you don't have to suffer as much from either.

With a chronic illness you're more vulnerable to hurt feelings than you would otherwise be. Because of all that goes on inside you, both physically and emotionally, you have a greater need for consideration and signs of concern and caring than you would if you were well and healthy. So when family members and friends don't respond to you in these "understanding" ways, your feelings are hurt.

It may seem that your feelings are hurt by what someone says or does - and that's all there is to it. But that's not all there is to it, not by a long shot. Your feelings are hurt, not by what the other person says or does, but by the meanings you give to

what the other person says or does. Different meanings – different feelings.

Your feelings are hurt when a family member or friend says or does something which you take to mean, he's not interested in how you feel, he's not concerned about you or he doesn't care. The meanings you give come from your understanding of the thoughts and feelings expressed in what the other person says or does – which may or may not be what the other person actually thinks and feels.

A fuller and more accurate understanding of how family members and friends are affected by your illness and what they actually think and feel may alleviate some of your hurt feelings.

Your Marital Partner

If you're married, it's the reactions of your partner that affect you most. Similarly, it's your partner who is the most affected by your illness. In speaking of the effect of

your illness on your partner, it should be pointed out that there tends to be a difference between the way wives react and relate to an ill husband and the way husbands react and relate to an ill wife. Women, by and large, are more prepared to accommodate and care for an ill partner than are men.

Beginning with doll-play, girls traditionally are raised to take care of children and later as wives are expected to administer to the physical and emotional needs of their husbands - sick or well. Not only that, being an understanding and caregiving person is a more important part of a woman's identity than it is of a man's. Therefore, accommodating to the emotional and physical needs of an ill husband is not only more acceptable to women than to men, but is more likely to be taken as more of the same.

The unfortunate consequence of this difference, to the extent that it is present, is that more women than men are hurt by

their partner's way of relating to their illness. The comments that follow, therefore, are addressed primarily to chronically ill wives but may pertain to husbands as well.

Your husband is likely to have complicated feelings related to your illness. He may, for example, be worried about you and afraid you're going to die. And to lessen his fears and yours too, for that matter, he may play down your illness or deny it altogether. He may feel helpless and bewildered about what to do for you and feel inadequate as a caregiver. And if he has never been seriously ill himself, he may be baffled by your reactions to your illness. Even if he has experienced an illness himself, men, by and large, tend to react to and cope differently with physical ailments than do women.

But regardless of his ability to understand what your illness is like for you, he doesn't want to say anything that might hurt or upset you. He's therefore likely to keep his feelings to himself. Or he may be the kind of person who keeps his feelings to himself in any case. Be that as it may, you may experience him as distant and withdrawn rather than as concerned and caring.

To complicate matters more, he's also concerned about himself, which he's even less likely to talk about. While he's saddened by what has happened to you and your life, he's also saddened by the changes in his life as well. After all, you're not as available to him physically or emotionally as you used to be and, more likely than not, he feels deprived and resentful. But what can he say? He knows it's all because of your illness, which neither you nor he, nor anyone else can do anything about.

What may be especially hurtful, if it happens to be the case, is your husband's diminished sexual interest in you. Whether you're interested in sex or not, you want him to find you physically attractive. With a chronic illness, it's hard enough to feel desirable as a wife, but it's much harder if your husband loses sexual interest in you.

I'd like to point out, however, that if your husband is worried and depressed by your illness, his sexual needs may also be depressed. And even when he is sexually interested, he may conceal his desire out of concern for you. After all, he knows that your fatigue, your discomforts and your pain may be upper most on your mind. But if you're

unaware that his sexual avoidance may be related to his consideration for you, you'll feel unnecessarily rejected, hurt and resentful.

In some instances, of course, the effects of a chronic disease do, in fact, diminish a husband's sexual attraction to his wife. When this occurs, he also experiences a sexual loss and wishes it were otherwise. However, this doesn't necessarily mean that he loves you any less.

Ironically, if your husband approaches you with some frequency, you may also feel hurt and resentful. You may feel he's not sufficiently sensitive to your physical condition and is primarily interested in satisfying his own needs. In this area it may be that he can't do anything right.

All in all, given what goes on inside him – and much more goes on inside him than what I've mentioned – he may not always respond to you with the sympathetic understanding you need. Unfortunately, when you were given the diagnosis of the disease, he wasn't simultaneously given the emotional wherewithal to deal with it. However, the more fully you understand your husband's thoughts and feelings related to your illness, the less likely you'll be hurt

by misconstruing the meaning of what he says or does.

In addition to trying to understand your partner's thoughts and feelings related to your illness, it is important for you to help him understand yours – not by accusing him of being insensitive and inconsiderate but by being as open as you can about how your illness affects you emotionally. Mutual understanding in a marital relationship is difficult enough, but the addition of a chronic illness requires all the understanding that both the ill and the well partner can come by.

Unfortunately, in some instances, hurt feelings don't come from a lack of understanding but from the well partner's inability to feel the compassion and concern that the ill partner requires. Even before your illness, your partner may not have been particularly thoughtful or considerate, but it didn't matter to you as much then as it does now. Or maybe he's changed since your illness and no longer has the feelings for you he once had. This, of course, is the most hurtful of all.

If this happens to be the case, marital counseling may be helpful if your husband is

willing. But whether he is or not, you may have to reconcile yourself to the realization that he doesn't have the feelings required to give you the emotional support you need. In that case, you may feel trapped with an illness in an unhappy marriage. But you wouldn't dare leave because you can't imagine who would want you in your condition.

However, your husband doesn't have to be your only source of understanding and support. You may be able to get the understanding and support you need from friends or other family members or from an emotional support group for people with your disease. Or as I will write about next time, you need to develop your own inner resources for coping with your illness and thus become less dependent upon emotional support from others.

Your Children

The way your adolescent and grown children relate to you since your illness may also hurt your feelings. They may show little interest in how you feel and may even have distanced themselves from you. If this is so, keep in mind that at their stage of development, they're still likely to be self-involved. Adolescents are troubled with

problems of growing up, and grown children are involved in establishing a longterm relationship. If they're married and have children, they may be troubled with marital or child-rearing problems of their own. The last thing in the world they need is a sick parent to be concerned about.

Grown children, no matter how old, expect their parents to be here forever. While they may think of themselves as independent adults, in their unacknowledged fantasies, you're still their ultimate protector. Your illness threatens all this.

This doesn't mean you might not be able to clarify some areas of misunderstanding by trying to find out specifically how your illness affects them and by telling them how your illness affects you, both physically and emotionally. They may have difficulty being open with you as you may have difficulty being open with them, but openness leads to openness, and it's your first move, like it or not.

Your Friends and Relatives

With a chronic illness, it's inevitable you'll feel more hurt and alienated from friends and relatives than you would otherwise be. It's important to keep in mind however, that there is no way a person

without a chronic disease can understand what it's like to live with one. But why should they understand, they don't have a physical ailment – you do. It's difficult for anyone to understand what he's never experienced. Even with the best of intentions, friends and relatives are going to say and do things that hurt your feelings.

For example, they may ask how you feel when you don't want to be reminded of your illness, or they may not ask how you feel when you want some sign of concern. They may not comfort you when you need, it or may be over-solicitous when you're feeling fine. They may not listen to you when you need to talk or listen only impatiently when they do.

If you're visibly affected by your illness, they may pity you – which is demeaning. Worse yet, they may physically distance themselves from you, as if you were contagious. On the other hand, if your illness doesn't show, they may act as if you're not sick at all and expect you to be the same as you always were.

Whether your illness shows or not, your friends and relatives may not understand why you have to break appointments at the last

minute. They don't understand “good days and bad days.” And since they don't understand, they may not invite you to some activity they think you're not up to. But whether you're up to it or not, you want to be invited anyway, and your feelings are hurt when you're not.

As with your husband and children, you may not fully understand how your illness affects your friends and relatives, and you may, at times, misconstrue the meaning of what they say and do. Only by openly talking with them about how their behavior affects you, and by learning how your illness affects them, can you find out what's really going on. To be realistic, however, don't expect complete understanding from friends and relatives, otherwise you'll continue to feel disappointed and hurt.

But what's most hurtful of all is the rejection of friends you don't hear from anymore. How could they abandon you when now, more than ever, you need friends who care? Unfortunately, you have no choice but to grieve the loss of friends brought on by your illness and try to make new friends, as difficult as it may be with your illness.

You're Single

If you're single and trying to meet people and establish a relationship, you're especially vulnerable to hurt feelings. If your illness shows, your feelings are hurt when someone you're interested in turns away from you. If your illness doesn't show, you have the problem of when and what to say about your condition. And when you do decide to tell a person you're going with out your illness, and he loses interest in you, you're not only hurt but devastated.

This rejection is especially hurtful because it confirms your feeling of being undesirable. To relieve your hurt feelings, you need to develop a sense of worth as a person with an illness. As I've already indicated, I'll write about this next time, and in subsequent essays, I'll write about the problems of being single with a chronic illness.

Your Parents

In some cases your parents may also be a source of hurt feelings. When you were sick as a child, one or both of your parents may have been caring and comforting. Now that you're ill as an adult, your parents may not be there for you as they once were.

Your parents, in their present stage of life, are likely to be worried about matters that didn't concern them when you and they were younger. They may be concerned about their own physical ailments and uneasy about how much time they have left. Or if it's not their own health and life they're primarily concerned about, they may be worried about the health and aging of their partner. This frightens them with the prospect of living the rest of their life alone.

Your parents are not likely to tell you, their "child", about these and other fears related to aging. This doesn't mean you can't initiate such a conversation. This would not only enable you to understand them better but, in all likelihood, would bring you closer together. Here, as in your other relationships, the more completely you understand what your parents are going through, the less likely you'll feel hurt by their selfinvolvement and their seeming indifference to your illness. In fact, you may even discover that their feelings are hurt by your not taking greater interest in their ailments.

The situation is different, however, if your parents were never particularly understanding or caring.

Their lack of present concern is likely to evoke old hurt feelings. It's also likely to evoke feelings of being unworthy now as it did when you were a child. If that's the case, you have more to understand about yourself and your relationship with your parents over the years. Keep in mind, however, it's unlikely you'll be able to get from them now what you didn't get from them before. But you don't have to blame yourself for it.

When All is Said and Done

It's your responsibility to establish and maintain the best relationships you can in spite of your illness. This includes learning as much as you can about how your illness affects others emotionally and helping them understand how your illness affects you emotionally as well as physically. You may even learn, in the process, that you're putting people off by the way you're acting. If that's the case, you may have to change some of your ways if you're going to get the understanding and consideration you want.

But even if you change your ways and increase your and other's understanding of the emotional effects of your illness, you're still not likely

to get all the support you want.

It's therefore important to strengthen your inner resources for coping with your illness. By strengthening your own inner resources, you would have less need for emotional support from others and, as a consequence, would be less vulnerable to hurt when you don't get it. To strengthen your inner resources, you need to discover and develop your value as a person with a chronic illness and evolve a life-sustaining purpose. I'll say more about this next time.

I realize personal development, whether you're ill or not, is a difficult prescription, but I'm talking about something important – your life fulfillment.

Dr. Mark Flapan has scleroderma and is Founder of the Scleroderma Federation of the Tri-State Area. He is a psychologist with a special interest in the emotional effects of chronic illness, both on the ill person and on family members. Used with the permission of the National Organization of Rare Diseases and the author, Mark Flapan, Ph.D.

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