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Living with a Rare Disorder – III

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

by Mark Flapan, Ph.D.

In two previous issues of *Orphan Disease Update* I wrote about self pity, self blame, guilt, shame and hurt as distressful feelings you don't have to live with. In this issue, I'll write about the feelings of anger you don't have to live with either.

Anger, with the possible exception of fear, disrupts the human body more than any other emotion and should be labeled, "dangerous to your health." Similarly, anger disrupts human relationships more than any other emotion and should be labeled, "dangerous to your social well being." Anger takes its toll on both the human body and on human relationships whether or not you have a chronic illness. But with a chronic illness, more than without one, you need your body working for you and you need supportive relationships with family members and friends as well. So no matter how you look at it, it's to your advantage to live with the least possible amount of anger. Therefore, in this article I'll suggest

ways of understanding yourself and ways of relating to others that may help you lessen your anger.

You Get Angry at Yourself

If you have a Chronic illness more things anger you than if you were well and healthy. You may get angry when frustrated by tasks you find difficult or impossible to do – tasks which everyone else can do without a second thought. You not only get angry at the object of your frustration but you get angry at yourself as well. If anyone else got angry at you for the same thing, you wouldn't take it – but you take it from yourself. You take it from yourself because you feel you should be able to do whatever you need to do – disease or no disease.

To put it a little differently, when you can't live up to the "shoulds" in your head you get angry at yourself. However, if you could set aside your judgmental "shoulds", you would more willingly accept the limitations of your illness.

While accepting your limitations won't make your tasks easier physically, it would certainly make them easier emotionally. You would then no longer berate yourself in anger when up against some difficult task, but would be patient with yourself instead.

You Would Like to be Treated Special

You not only have "shoulds" for yourself but you have "shoulds" for other people as well. So when others don't act toward you in ways you think they should, you're as hard on them as you are on yourself. After all – fair is fair.

You may get angry at people who don't treat you in some special way. You feel like the world owes you something because of your illness and you should be compensated somehow. As a child, your parents may have given you special consideration when you were sick, and now that you have an illness. you still expect to be treated special. As it happens, you're not a child anymore and others are

not your parents, so these expectations are not likely to be met. Even though you feel you've been cheated out of a normal life by your illness, nobody owes you anything because of it.

It may not make sense, but while you would like to be treated special, you still want to be taken as a normal person – no different than anyone else. You don't want to be related to as an invalid or pitied in any way and you get angry at anyone who does. At times it seems as if no matter how others react to you, it's not right somehow.

Friends and Relatives Don't Understand

You may be angry at friends and relatives who aren't as sensitive to your feelings as you think they should be. But why should they be that sensitive to your feelings? How can they understand what, it's like to live with a chronic illness. They don't have a disease – you do.

It may be hard to accept that well and able-bodied people don't know how to relate to someone with a chronic illness. It's difficult for them to understand what they've never experienced. So even with the best of intentions, they're going to say and do things that anger you.

Not only that, if the situation were reversed – you were well and healthy and a friend had some rare disorder, you might not understand her feelings or know how best to relate to her either. So even though your heart was in the right place, you might say and do things that angered her just as your friends say and do things that anger you. I know you would like to think it would be otherwise, – maybe it would be or maybe it wouldn't.

Family Members Don't do it Right

Friends and relatives are one thing, but your immediate family is something else again. More likely than not, you're mainly angry at those you need and depend upon the most your husband, your adolescent or adult children or other close family members. You not only get angry at them for what they don't do for you, but more often than not, you get angry at them for what they do for you and for how they do it.

Even with good intentions, no one is likely to do things for you exactly the way you would do them for yourself, especially when it comes to your personal care. Besides that, no one is likely to do things for you as quickly as you would do them for

yourself. They may even forget to do some things altogether.

If, after many times, they still don't do things as you want them done – you get exasperated. And if you have to wait for what you need – you get impatient. So rather than appreciating what family members do for you, you end up being angry at them instead.

If this happens to be the case, it may be you don't realize how much you expect from family members. Since you are your first priority, you expect to be their first priority too. And since you need them to help you with your life, you don't take kindly to their taking time out for their lives. This is most likely to be the case if your illness goes back to early childhood.

Even if your illness came later, you may have expected family members to do your bidding. But now, more than ever, you expect them to do your bidding and you get angry when they don't.

Be that as it may, anger toward those you need and depend upon is a high price to pay for holding on to what may be unreasonable expectations. To live with less anger, you have to see that your expectations take others'

needs into consideration. If they don't, you can either modify your expectations or you can continue being angry at family members for not being the way you want them to be.

Similarly, if you want to live with less anger toward yourself, you need to ease up on your expectations for yourself as well. This requires making your illness and the limitations that go with it an acceptable rather than unacceptable part of who you are. In other words, you need to develop an acceptable identity as "a person with an illness."

If you stop to think about it, to do the best you can do and to be the best you can be is more than enough to ask of yourself - with or without a chronic illness. And as an added benefit for accepting your own limitations you'll be more tolerant of others' "imperfections". In other words, the more you accept yourself for who you are the more you'll accept others for who they are. That's the way it works.

Your Doctor Doesn't Meet Your Expectations Either

With a chronic illness, you're not only dependent on family members but on your doctor, too. Although you're

dependent on your doctor for your physical well being, he affects you emotionally as well – and one of your emotional reactions may be anger.

You may get angry at your doctor because he doesn't make you better or even keep you from getting worse. Maybe you can't accept that your doctor doesn't know more about your disease and how to treat it than is medically known, that is, more than is written in medical journals and discussed at medical conferences. Maybe you can't accept there is no cure for your disease and you expect him to cure you. In either case, it's your unrealistic expectations, not your doctor's incompetence, that account for your anger. On the other hand, if your doctor is, in fact, not up on your disease, you should, of course, find one who is.

While you may get angry at your doctor for not doing more for you physically, you're more likely to get angry at him for how he affects you emotionally. He may be hard to reach on the phone, he may keep you waiting for hours to see him, he may rush you through appointments. He may say things that upset and frighten you or say so little you imagine all kinds of

frightening things. Worst of all, he may attend to your body but ignore your feelings.

It may be that your doctor is insensitive, inconsiderate and has little interest in you as a person. In this case, you would do well to find a doctor who is better for your emotional wellbeing – which is as important as your physical well-being for living with a chronic illness.

But maybe your expectations are inappropriate for a relationship between a doctor and patient. Maybe you expect him to relate to you as if you were his only patient. Maybe you expect him to have the interest, concern and caring for you he would have if you were his child. Maybe you expect him to be God. Discomforting as it may be, you are one of his many patients, you're not his child and he's not God.

But no matter how angry you get at your doctor, whether your expectations are appropriate or not – and you have to decide that – you can only affect his behavior toward you so much. You can't change him into someone he isn't. You can, however, either change your doctor or change your expectations of the doctor you have. Whichever you do, it's

better than making anger part of your medical treatment.

Hurt Feelings May Underlie Your Anger

You get angry at other people – family members and friends especially – not only because they don't act toward you the way you think they should, but because they hurt your feelings. In a previous *Orphan Disease Update* article I suggested ways of lessening hurt feelings by acquiring a fuller understanding of how your illness affects others and by helping others understand how your illness affects you, especially emotionally. What I suggested then would also calm your anger when your anger arises out of hurt feelings.

There are, however, additional ways to relieve anger arising from hurt feelings. This requires being aware of your hurt feelings and not just your anger, which you may not be. For one thing, anger tends to blot out hurt feelings. For another, anger focuses your attention on the other person – what the other person did or didn't do, while hurt feelings focuses your attention on yourself – what you need but didn't get. Besides that, in anger you feel selfrighteous, while in hurt you feel

dependent and vulnerable. You are, therefore, more likely to acknowledge anger than hurt because you feel better about yourself when you do. This is especially so for men who consider anger a sign of strength and hurt a sign of weakness.

However, by revealing your hurt feelings rather than expressing only your anger, you're more likely to improve the situation with the other person. Blaming someone in anger, more often than not, evokes a defensive or angry response, while revealing hurt feelings tends to elicit a more sympathetic and caring response. This is so, because no matter why the other person said what he said or did what he did it's unlikely he wanted to hurt your feelings.

There is another advantage to acknowledging hurt feelings. In anger, whether you express it or not, you hold the other person responsible for your feelings. While in acknowledging hurt, even if only to yourself, you're more likely to assume some responsibility for your feelings. This is so, because in acknowledging hurt feelings, you're more apt to recognize your own unfulfilled need for consideration, understanding or sympathy as underlying your hurt and anger.

If you assume responsibility for your feelings you don't have to depend solely on the other person changing his ways for you to feel better. You can feel better by changing your expectations of what the other person is supposed to say or do to satisfy you. This is important because your own expectations are more in your control than the other person's behavior.

You May Cause the Behavior that Makes You Angry

There are still other ways you can improve the situations with those who anger you. It's possible, that in one way or another you put people off and they then act toward you in ways that make you angry. Maybe you're not doing everything you can to make yourself better, physically or emotionally. Maybe you ask others to do things for you, you could do for yourself. Maybe you expect others to read your mind rather than asking for what you want. Maybe you're so demanding no one can do enough for you. Maybe you don't express appreciation for what others do for you and they resent your ingratitude. And who knows what else?

If you can increase your understanding of how you

relate to others and guide or modify your behavior accordingly, you may evoke responses in others that are more to your liking. Isn't taking a good and understanding look at yourself worth living with less anger? I hope so.

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