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Living with a Rare Disorder – I

What do you need to know about your illness? (Part 1 of a 3-part series)

by Mark Flapan, Ph.D.

Are you the kind of person who wants to know everything you can about your illness or would you rather not know any more than necessary? It's generally assumed that the more you know the better. You're encouraged to ask your doctor questions, to read all you can about your disease and to attend meetings related to your illness. If you're not interested in becoming such an "informed patient" you may be accused of "denying your illness."

What you know or don't know about your illness not only affects how you take care of yourself physically, but how you live with yourself emotionally. What you know depends on what you want to know, which may be more or less than you need to know for your physical and emotional well-being. What you want to know, in turn, depends on the kind of person you are and how you deal with your illness. It's important for you and those close to you to understand and respect your

desire "to know" or "not to know" since these are fundamental to your way of being. But it's also important for you to understand yourself well enough to determine whether your desire to know or not know is in your best interest physically and emotionally.

You Want to Know Everything You Can

You must be the kind of person who wants to know everything possible about your illness. No matter how much your doctor tells you, it's never enough. This is especially so if you have a doctor who tells you can only learn so much from your doctor, so you read everything you can get your hands on, attend meetings where doctors give talks about your disease and talk to others who have the same illness as you do. When you first learned you had a chronic illness, you couldn't believe you had it – certainly there had to be some mistake. So you read up on the disease to see for yourself whether you actually had

what the doctor said you had – hoping, of course, you didn't.

When you finally accepted the fact that you did, indeed, have a chronic illness, you couldn't believe there was no cure. There had to be a cure somewhere, so again you decided to look into the matter yourself. You called people and tried to find out what you could about whatever research was going on and about any experimental treatments. You even tried to find out if there were drugs for your illness in Europe not approved for use in the United States. You left no stone unturned trying to find a cure – nutrition, vitamins, acupuncture, relaxation techniques – you name, you looked into it.

To this day you try to find out all you can about available treatments so you'll know you're getting the best treatment possible. You don't want to depend only on your doctor for this. You want to keep up with ongoing research to learn if a cure is on the horizon. You attend meetings about your illness hoping to

hear of some new treatment. You don't want to miss out on anything that could help you. If you're a person who doesn't like to take drugs, you may need to know the possible side effects of suggested medication. You look these up yourself, just to make sure the effects of the treatment aren't worse than the disease.

You also talk to others who have the same illness. You want to find out if they have symptoms similar to yours and how your symptoms compare to theirs. You want to find out how much worse your symptoms can get and if they ever get better. You also want to learn what medications others are taking and what else they're doing for themselves.

But What's the Value of Knowing so Much?

Needless to say, knowledge about your disease evokes fears of symptoms and complications you may never get. You were certainly frightened reading about your disease in medical books and you were upset by seeing slides doctors showed at meetings you attended. It's impossible to learn what might happen in your disease without imagining it will happen to you. It's still more frightening to learn what's

happening in your own body. Even when your doctor doesn't say anything upsetting, you start to worry if, after he's examined you, you sense he's concerned about something. You were shaken when he told you about a new development. You not only had something old to worry about, you had something new to worry about. But even if it upsets you, you still want your doctor to tell you everything.

So what's the point of knowing so much? A greater understanding of your body and your disease enables you to ask more sensible questions of your doctor and to more easily understand and remember what he tells you. The more you understand how your body is supposed to work, the better you're able to report physical changes that are relevant, and the less troubled you are by changes that may have no consequence. The way you see it, what you know and say to your doctor makes a difference in the kind of medical care you get. Also, you don't like having to rely completely on your doctor's remembering everything related to your "case." He has many patients to keep in mind, and even with his notes in your medical record, he may forget some aspects of your condition or

treatment. As it happens, you have only one person to keep track of – you – and you feel more secure when you keep your eye on things yourself.

It's upsetting to have strange things happening to your body with little understanding of what's going on. But regardless of how much you know about your symptoms, it's still distressing to feel and see your body changing before your eyes. But somehow, it's a little easier to come to terms with changes in your body if they're not so mysterious.

Knowledge about your illness, and how it's affecting you, lessens your feeling of helplessness and enables you to feel more in control over what might happen. Although greater knowledge may not, in fact, give you this control, it relieves some of the apprehension related to the "unknown" You would rather come to terms with the worst, whatever it might be, than live in the dark not knowing what might happen. So even if you're upset, frightened or depressed by what you learn, there are many reasons you want to know everything you can about your disease. You just wish your whole life didn't revolve around your illness. Sometimes you feel you're so taken up with your physical condition that nothing else in the world

matters. It's hard not to be preoccupied with yourself when scary things are happening to your body. But at other times, you wish you could get on with your life so you wouldn't miss out on so much.

You Want to Know only What you Have to Know

You may, on the other hand, be the kind of person who doesn't want to know any more than is absolutely necessary about your illness. Even before your illness, if you heard about some medical disorder, you became frightened you would get it. You know your imagination would run wild if you knew too many specifics about your disease.

For you, coping with your illness depends on remaining as hopeful and optimistic as possible. You want to maintain a positive attitude and for you "not knowing" helps. You prefer to deal with developments as they come along, rather than worrying about everything that might happen. After all, none of these things may ever happen to you, so why do you need to know about them?

What can you do with more knowledge about your condition, anyway? Knowing about the intricacies of the

disease won't make it go away. So what's the point of knowing more than you have to, when it only frightens and upsets you?

So to keep from getting frightened or depressed, you don't want to read about your illness or listen to doctors talk at meetings about the disease. And you don't want to meet others with the same illness and get upset by seeing their symptoms or hearing the details of what's happened to them. In general, you would just as soon not think about your illness any more than necessary – it's on your mind enough already, so why dwell on it?

As a child, when you were sick, you were comforted by a caring mother and treated medically by the family doctor. Now that you have a chronic illness, you still wish you had a mother to comfort you, whatever your age. And you certainly want a concerned doctor to take care of you.

Although you feel secure relying on your doctor to tell you whatever you need to know, you prefer he not tell you too much. The doctor who diagnosed your condition may have scared you to death by telling you all the things that could happen. Maybe you were so unfortunate as to have

a doctor tell you how many years you had to live – and you believed him. This "knowledge" threw you into such despair you gave up before you got started.

Since then, you've learned such predictions aren't the last word. But his words still linger on in your mind – unless, of course, you've already outlived his dire prediction.

While you depend on your doctor to take care of you, you don't want to see him anymore than necessary. You may go so far as to avoid mentioning some new symptom to your family, because they would insist you make an appointment, and you're afraid your worst fears will be confirmed.

You even ignore new symptoms or try not to notice old symptoms getting worse. You're hoping nothing is seriously wrong, or if something is, it will go away by itself. You know you shouldn't put off medical attention by ignoring what's going on, but you do it anyway – you're so afraid of what you might find out.

When you do finally see your doctor, you don't ask too many questions for fear of becoming upset by what he tells you. So a family member

sometimes comes along to ask whatever you may need to know.

Your security comes from faith in a knowledgeable and concerned doctor who's in charge of your medical care, and who will do whatever has to be done. You're most comfortable relying on his knowledge and putting yourself in his hands rather than having to know it all yourself. When a new treatment comes along, he'll certainly hear about it, and will let you know if it can be of any help to you. That's what you have a doctor for, isn't it?

So What do You Need to Know?

Whether you would like to know as much as possible about your illness or don't want to know any more than necessary, it's important to be able to do the things you have to do to take care of yourself. You've probably read or been told by your doctor how much rest and exercise to get; what foods, if any, to avoid; whether or not vitamins can help; when to take your medications before, after or between meals; and what to do if you forget to take them, and there may be many practical suggestions about how to "manage" your disease. For your best

physical care, it's important to know about these.

Knowing More is up to You

How much more you actually need to know about your disease is more emotionally than physically relevant. What best enables you, particularly, to cope with your illness, depends upon how you react to crises, and a chronic illness is a series of crises.

You may be neither the kind of person who wants to know everything nor the kind who wants to know only what's necessary. You may be somewhere in between. What's more, your desire to know may change through time. If, at first, you want to know everything possible, your desire to know more may lessen as you sense that with or without your knowledge, your disease has a life of its own. On the other hand, if at first you wanted to know as little as possible, you may become more comfortable learning more, as you're increasingly able to face the reality of your illness.

But if new symptoms suddenly emerge, your desire to learn all you can about what's happening or your inclination to rely only on your doctor to tell you what you need to know is likely to

re-emerge. Wanting to know everything or wanting to know only what is absolutely necessary are both ways of coping with fear. And the progression of your disease certainly evokes fear.

In any case, the kind of person you are and your characteristic way of coping with fear are not likely to change dramatically because you have a chronic illness. And as I said before, you, as well as those close to you, need to understand and respect the way you are. However, it's also up to you to understand yourself well enough to decide how much you should know for both your physical care and your emotional well-being. When all is said and done, who can decide this better than you?

Dr. Mark Flapan has scleroderma and is President of the Scleroderma Society. He is a psychologist in New York City and has a special interest in the emotional effects of chronic illness both on the ill person and on family members. Used with permission of The National Organization of Rare Diseases and the author, Mark Flapan, Ph.D.

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