

NATIONAL MULTIPLE SCLEROSIS SOCIETY
MS LEARN ONLINE INTERNET PROGRAM
TOGETHER IN THE MS JOURNEY #2

>>Welcome, and thank you for joining the National Multiple Sclerosis Society's MS Learn Online Internet. We are back with the second and final segment of *Together in the MS Journey*, a series devoted to couples living with MS. If you missed the first program, we encourage you to listen to it by clicking on the link that says additional MS learn online web casts.

To guide us through today's program is MS Learn Online correspondent Dr. Rosalind Kalb.

>>**Dr. Kalb:** Hello. I am very pleased to be here with you for this webcast. As a clinical psychologist and Director of the Professional Resource Center of the National Multiple Sclerosis Society I know the importance of today's topic. I am very pleased and honored to have with me a friend and colleague, Dr. Peggy Crawford. Dr. Crawford is a clinical psychologist at the Mellon Center for Research and Treatment of MS at the Cleveland Clinic Foundation.

I really appreciate you being here with me today, Peggy.

>>**Dr. Crawford:** Thanks, Roz, glad to be here. The focus of our program today is on communication. You know, an effective communication is considered an important component in relationships in general. Why do we think it is so important for couples in which a partner has MS?

>>**Dr. Kalb:** I think communication is important, as you said, for every couple. I think that life gets more complicated when MS enters the picture. It has the potential to impact virtually every aspect of family life, so couples need to be able to share their feelings about that. They need to be able to talk with each other about the kinds of ways that MS is impacting their daily activities, their priorities for their relationship, and problem solve together. Communication is really what ties all that together and makes it possible, I think, for couples to meet the challenges that MS brings.

>>**Dr. Crawford:** Can you give us a sense in your experience of what are some of the most important MS related issues that you feel couples really need to discuss on an ongoing basis?

>>Dr. Kalb: I think, first and foremost, they have to have a sense of what MS is. They need to know what the disease is that they are dealing with. We know that MS can create a lot of different kinds of symptoms, many of which may be invisible and may not be well understood. I think if couples start with a basic understanding of the disease that they get through printed information about it or going to educational meetings, asking questions of the doctor, they at least have some shared understanding and some vocabulary to talk about what it is that is going on. I think the fact that so many of the symptoms of MS, particularly fatigue, weakness, cognitive symptoms, mood issues, are not clearly visible makes it even more important to talk about them because the partner who does not have MS cannot begin to understand what is going on just by looking at the person he or she is with. There has to be talking and sharing of information in order to be able to deal with all of that. I think, also, that when something like MS comes in and interferes with your life everyone has feeling about it--feelings of grief over things that are changed about daily life or the loss of the ability to do certain things or share certain activities. There are also resentments and angers and guilt when people cannot do things the way they used to be able to them or guilt over some of these angry feelings, so without communicating, without an open discussion of some of these feelings, they can tend to build up and interfere with communications. So we want to encourage people to find comfortable ways to talk about some of these feelings. I think in order for couples to be comfortable and effective together they need to be partners in the life they have. So talking about their partnership and how MS and its symptoms have the ability to impact that partnership is also something that is critically important for them to be able to talk about.

>>Dr. Crawford: What kinds of things tend to interfere with effective communication?

>>Dr. Kalb: I think there are quite a few obstacles that I have seen in the families that I have worked with. First and foremost is that information piece that if people are not educated about MS, do not have the vocabulary to use to talk about it, it is difficult. I think also the feelings that I mentioned, the grief and the resentments and the guilts that come up are difficult to share. People are not always comfortable talking about feelings like that and that can get in the way. I think also that people who love each other are often feeling like they need to protect one another. So when difficult topics come up and the person is very worried about hurting someone else's feelings they may say: well she is upset enough today about what is going on with her MS, I do not need to make it worse by talking about how

I am feeling. Or he is so stressed out about things at work I do not need to be talking about my MS. There is a hesitation to bring up any subject that might make somebody else uncomfortable.

>>**Dr. Crawford:** So when people are having this kind of difficulty, are there things that you can recommend to couples that they can even sort of, diagnosis is not really the word, but evaluate their own communication? How could they do that at home and know whether they are in trouble or not?

>>**Dr. Kalb:** I think that if people find themselves starting to talk, starting to bring up a subject and stopping, that is a flashing red light. It means that it does not feel comfortable to bring something up that needs to be said. In other words, if people find themselves swallowing their thoughts a lot and not expressing what is on their mind, that is a signal that there is something that is getting in the way of talking. I think if people find that they are just not talking as much, not spending as much time together, that sometimes that means that there is this gap growing because they have not been talking and communicating, and that is a good signal. If people are feeling angry a lot of the time and sort of wondering where that anger is coming from and what the resent is about or if they are feeling lonely, those are signals that communication is not happening the way it should and they might want to look at what is going on.

>>**Dr. Crawford:** Sometimes one of the things I have heard from couples too is that if there is strong emotion that comes up once they start talking that often, as you said, is something people are uncomfortable with and so then the discussion stops, and people sometimes misinterpret that and I have heard that many times between couples that I do not want to make her cry so I do not bring it up. Then the other person misinterpreting that as you do not every want to talk about my MS.

>>**Dr. Kalb:** Yes, I think that people with MS can often get concerned when their partner does not talk about it that they do not care. I agree that that is a significant issue because frequently when people do not bring up a difficult topic it is not because they do not care, it is because they simply do not know how to bring it up.

>>**Dr. Crawford:** Sounds like this is an incredibly common problem. It is a good thing that we are talking about this because I am sure that everybody can really connect with this. This is such a generalized issue whether people have MS or not, but as we say particularly when you have MS.

>>**Dr. Kalb:** Another obstacle to communication that I think is important to talk about is that sometimes people are not aware when their relationship is being impacted by the symptoms of MS. Sometimes the changes can happen so gradually or be so subtle that there are changes in the relationship, changes in their roles around the house, with their children, and all of a sudden they feel like there is a crisis but they do not know where the crisis came from. I think it is important for couples to try to stay in communication as they notice things that may be changing or may not be feeling so comfortable between them so that they pick up on some of these changes before they get to a crisis point.

Another obstacle that I think is critically important to talk about is the subtle or not-so-subtle struggle that some couples get into about who has it worse. There is the person who has MS and is feeling really devastated by this change in his or her life and all the ways that the symptoms we have talked about impacting daily life. And then the partner who sometimes feels as though his or her whole life has been turned topsy turvy by a disease that is really the other person's. This kind of competition can interfere with couples sharing their feelings and talking about what is going on between them.

>>**Dr. Crawford:** It sounds like we are saying also that we want people to think about communication as a day-to-day function and not just something that happens periodically, but that people kind of need to attend to it on a regular basis like they do any other basic need. We are talking so much about encouraging people to communicate about MS and ways in which they can talk about it more openly; do you think it is possible for couples to talk too much about MS? In other words, for MS to be too much a focus of their lives?

>>**Dr. Kalb:** My feeling about MS in any relationship or any household is that you want to give it as much time and attention and energy as it needs but you do not want to give it any more than that. Any couple that finds itself talking only about MS or only focused on MS related activities or issues, that couple is missing out on other important things in their life and it can certainly become a focus of too much preoccupation I think.

>>**Dr. Crawford:** Sometimes when I have seen couples where that is the case, when you really get them talking about it, one of the things that seems to be driving that is just tremendous anxiety that if we do not talk about MS constantly and we are not thinking about it and trying to come up with strategies for dealing with it that some how we will be taken by surprise. That something bad will

happen. Sometimes just getting couples to talk about why they talk about it so much or why they are not talking about it is a useful exercise I have found.

>>**Dr. Kalb:** I think there is another issue here that is important. That is that sometimes communication stops in a couple or at least runs into problems in a couple when the person who has MS is so anxious and so worried about MS that that becomes a primary focus for him or for her. That partner finds it very hard to focus on anything else. When that happens, the partner without MS can start to feel as though his or her needs do not matter any more, are not of concern, and will start to feel not cared about, left out, and when that happens communication can really, I think, run into trouble. It is important, I think, for every couple that both members of the couple feel important, feel cared for, and cared about. One of the reasons that couples need to continue to communicate and to talk about the impact on their relationship is so that they can keep their partnership going in a smooth and effective way. Each person in a couple needs to feel like a contributing member of a relationship and each needs to feel like his or her needs are important.

>>**Dr. Crawford:** If we have gotten to the point where a couple has acknowledged that they have communication difficulties and they want to make it better, what kinds of recommendations would you make to them?

>>**Dr. Kalb:** I think there are several kinds of strategies that people can follow. I think that seeing a family counselor is always a good way to jump-start communication if that is a problem. If people are finding it difficult to talk to each other or finding it difficult to bring up some of these tough topics or share their feelings, it can help to have a third person in the room who kind of leads the way, sets the tone, and facilitates the conversation.

I think it can also be effective to just read about MS together. Read about some of these issues that we have been talking about today, seeing how other couples have handled it. Sometimes just the reading about it together brings up a shared recognition of what some of the problems might be and enables people to start talking. I think that support groups are also an excellent way. National MS Society chapters offer support groups and many of the chapters have groups for couples and it can be a wonderful experience to be in a group with other couples and recognize that what you are going through in your household as a couple is not so different from what is happening with other and you learn how other couples have managed some of these problems. You share problem solving strategies that you can then take home and try.

>>**Dr. Crawford:** Sometimes I have found that one person in a couple is not ready to venture out or to see a family counselor or even to go to a support group, but I still encourage the partner who is ready to do some of those things because they can still go home and have an influence. They can still share that information and they can work on communication. In many cases the other person ends up changing and becoming more open to those experiences. I encourage people that, whoever is willing at this point, it is a place to start.

>>**Dr. Kalb:** I agree with you and I give the same kinds of advice, and what I have frequently found is that once the one person who is ready does start the other person after a while gets curious and wants to find out what is being talked about and feels ready to venture out. I agree. I make the same recommendation.

Peggy, thank you again for being with us. I appreciate it and it was a pleasure to be here with you.

>>**Dr. Crawford:** Thanks, Roz, it is so important to talk about this communication issue.

Funding for this program was provided as an unrestricted educational grant from these National MS Society chapters.

If you have a question that was not addressed or if you would like more information on multiple sclerosis, check out the resources link below or call the chapter nearest you for an answer to your question. You can reach your chapter by calling 1-800-FIGHTMS. MS Learn Online is an internet program series that provides web casts on a variety of topics. To see other available web casts, click on mslearnonline@nmss.org.

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