



National Multiple Sclerosis Society
Midwest Regional Teleconference Series
"You Are Not Alone"
December 12, 2011

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Our Focus Areas

- Feelings of seclusion and isolation.
- Your experience with MS and what other people do and do not understand.
- Taking action, changing your relationship to feelings of aloneness and isolation, and creating your social support network.

A Night at a Concert



When Others Don't Understand

- "Why is it that you can do your work on some days and not others?"
- "We all get tired in the afternoon; what makes your fatigue so different?"
- "I know it is going to be 90 degrees today and I will be hot too but I still think we should go to the neighborhood picnic. Getting out will do you some good."
- "This is the second time you cancelled lunch; I don't understand what 'having a bad day' means."
- "There is a handicap parking spot in front of the restaurant and we have your wheelchair. We are all set for a great evening"
- "My colleague's wife has had MS longer than you have and is doing much better. Have you been taking your injections? Is there something else we should be doing?"

Why Others Don't Understand

- Lack of knowledge about the condition and/or unwillingness to learn something about the condition, perhaps due to their own fear and anxiety.
- Attempts to manage their own anxiety through micromanaging you.
- Minimizing and denying or exaggerating the impact your condition has had on them.
- Attachments to the past and fears of the future.

What Can You Do When Others Don't Understand

- As best you can start by honoring the validity of your experience as it is right now.
- Suspend your own self critical judgment.
- Some people will want to understand better and some just won't.
- We cultivate trusting relationships. As you come to know, accept, and trust your experience as valid, you may increasingly let others know who have the heartfelt desire to know.
- Just as you are trying to come to terms with a life changing condition your loved ones have a parallel challenge. It can be done. There is no one right way.

Aloneness

- “You can have a support system, a family, a spouse, kids, you can have friends who are involved with you, but when all is said and done, you are still alone with yourself. It’s just part of the illness.”
 - Richard M. Cohen, author of *Blindsided*

Isolation

- “I take for granted that everyone is isolated. And then I find out if it’s a problem.”
 - Dr. Norman J. Kachuck, Director of the MS Center at the University of Southern California.
- “I see how people hurt themselves above and beyond the disease. MS wreaks havoc. Then isolation, which is a secondary thing, happens to people and they don’t anticipate it, which can be devastating.”
 - Dr. Gail A. Murdock, Psychologist at the MS Center at the University of Southern California.

Acceptance and Living What is Needed?

- Ecklund and MacDonald, 1991
 - Accept the reality of the condition (MS).
 - Learn to live with the condition.
- Reynolds Price from *A Whole New Life*
 - “useful instruction in how to absorb the staggering but not quite-lethal blow that ends your former life and offers nothing by way of a new life that you can begin to think of wanting.”

What Can Be Offered

- Acceptance isn't a particular point to get to, but an ongoing process of trying as best we can to be with our experience as it is now.
- Suspend self-judgment and be with your life as only you can live it.
- We don't fight the reality of our condition nor do we fall victim to it. We change our relationship to MS by placing it within the context of a larger life to be lived.

You Can't Stop The Waves But You Can Learn to Surf



No One Size Fits All

“It is better to know the patient who has the disease than the disease the patient has.”

Hippocrates

- People living with MS may share a common diagnosis but their experiences with the condition are unique and represent a complex interplay of:
 - Medical and neuropsychological factors
 - Personality
 - Current circumstances including family and social support
 - Accessibility to treatment
 - Future perspective - hope

Some Possibilities to Consider

With possibilities there is hope and with hope there are possibilities

- Building a Foundation for an Attitude of Mind
 - Five Elements of a Way
 - Mindful Living
 - Cultivating Positive Emotions
- The Attitude of Mind approach isn't a quick fix but a way of living with the realities of MS including feelings of aloneness and isolation.
- Allow yourself to approach the lessons with an open and non-judgmental mind and let your experience be your guide. Remember many of the lessons have come from you.

Five Elements of A Way

Open Mind

- Feelings of aloneness and isolation are part of the life experience with MS.
- When you experience these feelings try as best you can to catch any reactions of judging yourself for having “negative feelings”.
- You may have had similar feelings in the past or maybe not, but they are here now and you can decide how you want to relate to them. And that may mean considering some possibilities you may not have considered before.

Five Elements of A Way Active Orientation

- Be with your experience as it is and see what is going on.
- The first step to working with painful feelings like aloneness and isolation is to try as best you can not to push them away nor get carried away by them.
- Visits from family and friends can be very welcomed but everyone's circumstances are different and you can take different action steps depending on your needs and condition for establishing and maintaining contact.

Five Elements of A Way Action Orientation (continued)

- Some possibilities to try:
 - Get out as best you can with friends and family. It may take longer to get ready, it may require some extra planning, it may require using a wheelchair, it may require knowing where the nearest restroom is, but above all allow yourself the flexibility to decide if today is a good day for you.
 - Don't wait to live. Invite friends or family over to your place.

Five Elements of A Way Action Orientation (continued)

- Some possibilities to try:
 - Phone contact. How about Skype?
 - Church and civic organizations
 - MS Society Activities:
 - Support Groups
 - Programs like the one you are listening to right now
 - Friendly Visitor Programs
 - Social Networking

Five Elements of A Way Action Orientation (continued)

- Some possibilities to try:
 - Allow your awareness to consider the possibility that you still are or can become a “caregiver”.
 - Parenting
 - Being a partner
 - Being a mentor
 - Providing care to a living thing that depends on you (e.g., pets, plants).

Five Elements of A Way Present Moment Awareness

- “Only the day dawns to which we are awake”.
Henry David Thoreau
- Try as best you can to cultivate present moment awareness to counter reactive patterns of being attached to the past with regret and yearning, or projecting a future filled with anxiety and fear.
- Let your senses be your guide to being alive here and now.
 - Sight, Sound, Touch, Taste, Smell.

Five Elements of A Way Process Perspective

- By not trying to get someplace other than where we are right now we realize that our lives are an unfolding process and everything changes.
- Adjusting to new challenges takes time and patience.
- Focus on taking small action steps. Drop by drop the bucket will get filled. Your life is in the filling; don't miss it while waiting for something else to happen.

Five Elements of A Way Balanced View

- Be as active as your condition and the day may allow.
- We don't fight realities but we also are not defeated by them.
- Know your limits; they are not your failings. By recognizing them you are less likely to be defeated by overload.
- The other face of isolation is solitude. Being alone and quiet can be restorative just like being engaged with others can be invigorating. It's all in the balance.

Mindful Living

- Be here for your life.
- Pay attention to the most simple acts of daily living.
- Aloneness can feel painful and sometimes the only available option is to be with it. At those times as best you can try to expand your awareness (sight, sound, touch, taste, smell) to the world around you. You may not erase the feeling of aloneness totally but after awhile it will diminish as it is surrounded by the larger world of your awareness and you are connected with it.
- Never forget that you are more than MS.

Cultivating Positive Emotions

- Positive Reappraisal
 - Reframing a stressful or negative situation in a positive light.
 - Wake up call of illness
 - What am I grateful for?
- Problem Solving Coping
 - Taking action where you can have an effect, one step at a time, with patience, and without self-judgment.
- Infusing Ordinary Events With Positive Meaning
 - It doesn't have to be extravagant; in fact striving for something memorable can obscure the very specialness that can make the moment memorable.

Isolation and Depression

- Depression in its various forms has been considered the most common mental state change in multiple sclerosis.
- Fatigue, cognitive dysfunction, and disability can contribute to depressed mood; and depression can be mediated by ability to participate in recreational activities.
- Feelings of being misunderstood, aloneness, and social isolation can contribute to depression.

Isolation and Depression continued

- Seeking professional help
 - Psychiatrist, Psychologist, Social Worker
- Remember the Attitude of Mind you have been cultivating:
 - Open Mind: It may be time for me to consider other possibilities for help.
 - Active Orientation: I can explore mental health referral options with my physician.
 - Present Moment Awareness: I want to engage in the life I have right now and I can use some help.
 - Process Perspective: I haven't failed. This is another step along the way of my living with MS and not being defeated by it.
 - Balanced View: My psychotherapist may not know my experience but she is willing to listen and be present as I face the challenges of acceptance, aloneness, and isolation. She helps me see possibilities and our relationship is a bridge of hope.

A Closing Note...