



# THE MYOSITIS ASSOCIATION

## *KEEP IN TOUCH*

# CENTRAL FLORIDA MYOSITIS KIT NEWSLETTER

October 2012 Newsletter

Please excuse me for being a little late (or a lot late) with this issue of our newsletter. As soon as I get more time I will send out some information about the Myositis Association's 2012 Annual Patient Conference that was held Sept.13 to 16, 2012.

The third quarterly Central Florida KIT was held at "The South Lake Hospital National Training Center" on October 6, 2012. There were 17 Myositis KIT members present plus our two presenters. Our group started arriving between 9:00 and 10:00 AM. Coffee, juice, fruit and two homemade coffee cakes were ready for them as they arrived. It was wonderful to see everyone again.



Our guest speaker this month was **Barbara Gaines**, who is the facilitator for the MS Caregiver's Support in The Villages, Florida. Her focus was on **caregiving**. Barbara spent her working career in the criminal Justice system. She worked 31 years as a probation officer, supervisor and adjunct professor at California Lutheran University teaching principals of probationary basics to other probation officers.



Barbara's real education as it relates to caregiving, started when, as the eldest daughter of her family, she took care of her mother during a debilitating illness. During this period her husband was diagnosed with MS. If that wasn't enough, her elderly father required her undivided attention as well. Barbara and her husband moved to The Villages in Central Florida about ten years ago. Her husband now requires much more assistance as he is now wheelchair dependent. Barbara has been active in the MS support group since 2006. In 2008 she took over the group as chief facilitator of the caregivers group.

Her power point presentation was organized and well received by all in attendance.

**These are some of the important topics she covered in her presentation:**

### **Caregiving is a Journey**

#### 1. Stage One- Heroic Stage

Diagnosis is in  
Productive Panic  
Consulting all the experts  
Optimism is strong  
Over time, hope slowly fades  
Optimism becomes despair

#### 2. Stage 2 Ambivalence

Supporting and caring for your partner is the right thing to do  
You are motivated by love, sense of duty, or societal expectations  
You are physically and emotionally exhausted  
Finances are strained  
Intimacy is difficult or impossible  
You don't see a future  
You feel fear, anger, sadness, resentment  
You compartmentalize your life  
You suffer total burnout, or  
You make real changes in your life and your approach to caregiving and the marital relationship itself  
Stage ends when you come to terms with reality and prognosis  
Resentment  
What have we given up—passions, hobbies, controls  
Life isn't what we expected it to be  
We are so used to looking after someone, we don't let them do for themselves  
How do we retrain someone we've pampered?

### **Retraining The caregiver**

Take time to do something for yourself  
Don't help unless asked  
Find something the person can do to feel/be successful  
The person being cared for  
Help the person build self-esteem by developing some independence  
Even persons with limited mobility can do some tasks; maintain some control of their environment  
Don't anticipate every move; let them do things that do not endanger them  
Provide time away from the caregivers  
Give yourself permission to have feelings –any feelings  
Understand why you have guilt—is there a mismatch between what you “think” you should be doing and what you are doing?  
Do you need to change your actions to align with your values?  
Meet your needs—if you need time to be alone, find someone to be with your loved one  
Ask for help!!!  
Understand that you will be a more effective caregiver when you take care of yourself  
Trust your instincts. Most of the time they'll lead you in the right direction.  
Caregivers often do a lot of lifting, pushing, pulling. Be good to your back.  
Grieve for your losses, and allow yourself to dream new dreams

### Tips for Family Caregivers

1. Caregiving is a job and respite is your earned right. Reward yourself with respite breaks often.
2. Watch out for signs of depression and don't delay in getting professional help when you need it.
3. When people offer to help, accept the offer and suggest specific things they can do.
4. Educate yourself about your loved one's condition and how to communicate effectively with the doctors
5. There's a difference between caring and doing. Be open to technologies and ideas that promote your loved one's independence
6. Seek support from other caregivers. There is great strength in knowing you are not alone.
7. Stand up for your rights as a caregiver and a citizen.
8. Trust your instincts. Most of the time they'll lead you in the right direction.
9. Grieve for your losses, and allow yourself to dream new dreams
10. Seek support from other caregivers. There is great strength in knowing you are not alone.

### Messages for Family Caregivers to Live By

- Believe in yourself.
- Protect your health.
- Reach out for help.
- Speak up for your rights.
- Stand up for your rights as a caregiver and a citizen.

Barbara is the facilitator for The Villages Multiple Sclerosis Caregivers' Support Group. She informed me to tell you that her group is open to any caregiver that would like to attend. The **Monthly Care Partners** normally meet the 4th Tuesday each month, 10:30 AM at the La Hacienda Center, 1200 Avenida Central, The Villages.

Barbara also gave me the web address to a Resource Guide. Remember it was written for people with MS, but there is a lot of useful information in it that we can all use.

The address is: [http://mssupportgroup.org/2012\\_MSVP\\_Resource\\_Guide.pdf](http://mssupportgroup.org/2012_MSVP_Resource_Guide.pdf)

We then broke for lunch, Salad, Chic-Fil-A, sandwiches and fruit. After lunch we separated into disease-specific discussion groups. The caregiver's group met with our speaker. Finally after about an hour we came back together and Dennis Platt made a short power point presentation on the "National Patient's Conference."



**Mark your calendar for the next meeting of the Central Florida KIT which will be April 27, 2013.**

**Change what you can, forget what you can't.**

**Dennis Platt**