

HOLISTIC CAREGIVING

- BODY, MIND AND SPIRIT –

by Hanni Epp, MA, LLP

Joyce was sobbing when she called. As I listened, she told me that her husband was diagnosed with Parkinson’s disease 15 years ago. “At first, Jim was able to do almost everything – he took his medicine and used common sense about the activities he participated in. Over time, he has become more and more limited in what he can do and his personality seems to have changed, too. Our whole life has changed because of the disease. I don’t know who we are as a couple anymore! I feel so afraid.”

About Joyce. . .

Joyce lives with her husband Jim in a home they have shared for the last 35 years. Both were teachers at the local high school. They have two children and one grandchild, all of whom live out of state. Jim took early retirement 8 years ago, and when Jim’s condition worsened, Joyce retired too.

Joyce and Jim had been active in the community throughout their marriage. Joyce had enjoyed singing with the local chapter of the Sweet Adelines, and had taught Sunday School at their church. Jim had coached the girls’ soccer team, and been involved in an environmental awareness group. They had also looked forward to their retirement years and had planned to do a lot of traveling. All of that had changed now.

What Are the Issues?

In all of their activities, and all of their planning, Jim and Joyce had never imagined how their lives would change. When Jim was first diagnosed, it was a setback, but the disease seemed manageable. For the most part, their lives went right on. Gradually, activities and associations were set aside as they became too much of a burden.

Now, Jim stays home most of the time, going out only for doctor's appointments. Joyce doesn't feel comfortable leaving Jim alone and neither one of them want a "stranger" in the home, so she also limits her outings to "necessities" – grocery shopping, the occasional beauty salon visit, etc., returning as quickly as she can, in case he has fallen or has other needs.

By now, Joyce and Jim have cut themselves off from the outside world. Jim is feeling awkward about being out in public because of his jerky arm motions and his unsteady gait. Although Joyce feels completely overwhelmed about having the sole responsibility for Jim's care, she feels strongly that no one else can give care to Jim as well as she can.

This new lifestyle sometimes has both of them feeling cheated, angry, resentful and guilty. They both miss their connections with the community, along with the pleasure that their activities brought to them. Also, they are sad that all the hopes and dreams they had for the future will likely never happen.

The fact is that their lives have become totally out of balance and they are hurting in many ways. Both of them are distressed in body, mind and spirit. By taking a holistic approach to their needs, Jim and Joyce may yet reconnect as a couple, and grow closer with family and friends, as well.

Where Do We Start?

The truth is that both the care giver and the care receiver benefit from holistic caregiving. But, sometimes our tendency to be as independent as possible can stand in our way. In Joyce and Jim's case, it almost seems that they were in denial at first; carrying on with all their activities as though nothing had happened. They chose not to get involved with the local chapter of the Parkinson's Association. They did not tell friends and family what was happening. This was the beginning of their isolation from the outside world, although they did not know it at the

time.

- Reaching out to the Parkinson's Association is a first step in re-entering the community. There they will find understanding people, and resources to address needs, questions and fears. They will meet other people with Parkinson's disease, and learn better ways to cope from people with experience, people who truly know what it's like to live with the disease. They may find themselves making new friends, and enjoying new activities!
- It's also time for Joyce and Jim to re-connect with old friends, with their former interests and with their spiritual lives. They may choose to see only a few friends to keep it manageable – but what a wonderful way to bring a fresh perspective into their lives, along with companionship and support. Taped church services and favorite sacred readings may help them rekindle their spiritual lives.
- During his coaching years, Jim had been very active physically. He loved to run and play soccer. Both Jim's medical advisors and the Parkinson's Association may be able to suggest activities to keep his body as fit as possible. Finding the resources within these two groups to help in this effort will be key to reducing the burden for Joyce. For example, perhaps there is an exercise class at the Parkinson's Association, or a track at a medical facility where Jim can safely walk (using a cane, if need be) while Joyce takes time to run an errand or enjoy lunch with a friend. Jim may want to follow soccer on the internet or on cable TV. Joyce may find a neighbor she can walk with, while keeping her pager with her, in case Jim needs help.

What's next...?

As their knowledge of community resources and contact with friends and family

increases, it will be but a small step to introduce Jim and Joyce to new ideas such as respite care and alternative therapies.

- Respite care can give families a break from each other; sometimes for a few hours, sometimes for a few days or more. The caregiver is able to release caregiving responsibilities to others for a time and participate in a desired activity – seeing friends, going to a retreat, etc. The care receiver may have another family member or a professional caregiver attend to his needs, either at home or at another location, ensuring his safety and wellbeing. Interest groups at the Parkinson’s Association or at an Adult Day Services Provider would be other possibilities to consider.
- Counseling could be very beneficial to Joyce and Jim as they find their way to a new and healthier way to care partner. Alternate therapies such as acupuncture and massage therapy can create balance in the body’s energy and bring relief from stress. All of these treatments can be very beneficial, and with a little research, providers can be found who will work on a sliding scale fee, or make other considerations to provide affordable treatment.

For some additional ideas, see the excellent Tips for Holistic Caregiving article by Michael Jankowski, MSW, elsewhere in this issue of *Mature Lifestyles*. Also, check out last month’s *Mature Lifestyles* for the Caregiver’s Corner article on Caring for Yourself; Health, Fitness and Nutrition.

Last thoughts...

It is easy to become so involved in the daily give and take of coping with a disease or disability that both care partners forget that this is only one aspect of who they are. We are

composed of body, mind and spirit. I would urge Joyce and Jim to take time to go beyond the focus on “body care” and attend to the needs of the mind and spirit every day. They, and you, are entitled!

References:

www.netwellness.com

www.painconnection.org

www.wegeinstitute.org

Caregiving: The Spiritual Journey of Love, Loss and Renewal. B.W. McLeod. 1999. Jossey-Bass.
Living Well with Parkinson's, 2nd Edition. G.W. Atwood, 2005. Jossey-Bass.

More resources

If you want more information about resources, the Caregiver Resource Network can help. The Network's web page (www.caregiverresource.net) can provide you with information about programs and services, fact sheets, and a questionnaire about caregiver strain. Or call Area Agency on Aging of Western Michigan (616) 456.5664, or (888) 456.5664.

If you have a question you would like to see addressed in a future article, feel free to contact Hanni Epp at: Caregiver's Corner, West Michigan Caregivers Alliance, 233 E. Fulton, Ste. 222, Grand Rapids, MI 49503, or e-mail at Hanni@wmichcare.com.

Column written by Hanni Epp, MA, therapist and consultant in private practice at West Michigan Caregivers Alliance. She is also a member of Caregiver Resource Network, a collaboration of West Michigan organizations dedicated to providing information and support for family and professional caregivers within the community. Be sure to look for the Caregiver's Corner in the next edition of Mature Lifestyles.