

Care Givers Session
The Myositis Association Annual Conference, Bellevue, WA - September 2007
Prepared by Ann Robertson, WA KIT Representative

I would like to salute all the care givers & care giving partners; and in doing so provide some resources and encouragement to help with your difficult and sometimes unseemingly unrecognized or unappreciated efforts.

At the TMA Annual Myositis Conference in Las Vegas, there was a wonderful seminar entitled "Living Well with Chronic Illness", put on by clinical psychologist Laury Goolsby. She introduced a new term describing the care giving relationship. That term was "Care Partners". This better represents a sharing and understanding that care giving is not a one way street but that it involves much more. It is the emotions, issues and commitments that both individuals not only share but also may have, see & feel differently. Many of these issues and emotions of the "care giving" partner will be the same things the ill or "recipient partner" is thinking about and dealing with, but they often are seen from different perspective.

For a care giving partner, this is a much more realistic and compassionate term for those unselfish individuals who do so much to help out the one they love. The ones who are sick with a chronic and often debilitating illness. It acknowledges that the person who helps care for a partner also has their own needs and feelings and those things need to be recognized by all involved, and in turn be dealt with.

On the other hand it also recognizes that the other partner, the one receiving the care is not helpless and has not become their illness. They are not less worthy or less of a person. It accepts the fact that they are thinking, spiritual, loving and caring partner that can give back emotionally to others and can also contribute to a situation or event, in other ways, even if they can not do the things physically they were once able to do.

Below are some reference suggestions to possibly help you, the care giver or "care partner" with your often difficult but appreciated role.

FAMILY CAREGIVER RESOURCE KIT

- **Order a Caregiver Kit by phone or email.** Call Aging and Disability Services Administration between 8 am and 5pm, Monday through Friday at 1-800-422-3263, or send an email to KorteLM@dshs.wa.gov. Make sure to include your name and mailing address.
- **Read the materials online.**
 - [Emotional challenges of caregiving](#)
 - [Family caregiver websites](#)
 - [Caring for a family member with a developmental disability](#)
 - [Helpful ADOSA caregiving publications and how to order](#)
 - [Tips for asking for and getting help](#)
 - [Caregiver's Handbook](#). A guide for family and other unpaid caregivers who care for an adult or senior with disabilities (PDF)

The [Caregiver's Handbook](#) (PDF) is a booklet published by ADOSA that includes down-to-earth information and resources for families providing care to an adult.

Let the receptionist know if you would like a copy when you call or include it with your email request or you can order it alone.

MYOSITIS WEBSITES

- **Jim Kilpatrick's Myositis Support Group** has a specific Caregivers Discussion Bulletin Board Forum - where you can post questions, thoughts or information and read what others have posted. www.myositissupportgroup.org/discussion.htm
- **The Myositis Association** – Caregiver's Support, great links & resources www.myositis.org/template/page.cfm?id=313

BOOKS & WRITTEN RESOURCES

- Beedle, Joyce & Dunn, Louise (Eds.).
The Carebook: A Workbook for Caregiver Peace of Mind.
Portland, Oregon: Lady Bug Press, 1991.
- Brammer, Lawrence & Bingea, Marian.
Caring for Yourself While Caring for Others: A Caregiver's Survival and Renewal Guide.
New York: Vantage Press, 1999.
- Brandt, Avrene.
Caregiver's Reprieve: A Guide to Emotional Survival When You're Caring for Someone You Love (The Working Caregiver Series).
San Luis Obispo, California: Impact Publishers, 1997.
- Hereema, Carol.
A Caregiver's Guide to Giving Medicines.
Upper Saddle River, New Jersey: Prentice Hall, 1999.
- Ilardo, Joseph & Rothman, Carole.
I'll Take Care of You: A Practical Guide for Family Caregivers.
Oakland, California: New Harbinger, 1999.
- Levine, Carol, (Ed.)
Always on Call: When Illness Turns Families into Caregivers.
New York: United Hospital Fund, 2000.
- Lipsyte, Robert.
In the Country of Illness: Comfort and Advice for the Journey.
New York: Alfred A. Knopf, 1998.
- McFarlane, Rodger & Bashe, Philip.
The Complete Bedside Companion: A No-Nonsense Guide to Caring for the Seriously Ill.
New York: Fireside, 1999.
- McGonigle, Chris.
Surviving Your Spouse's Chronic Illness: A Compassionate Guide.
New York: Henry Holt & Company, Incorporated, 1999.
- Meyer, Maria, Derr, Paula, & Hatfield, Mark.
The Comfort of Home: An Illustrated Step-by-Step Guide for Caregivers.
Portland, Oregon: CareTrust Publications, 1998.
- National Family Caregivers Association.
The Resourceful Caregiver: Helping Family Caregivers Help Themselves.
St. Louis, Missouri: Mosby, 1996.
- Olshevski, Jodi, Katz, Anne, & Knight, Bob.
Stress Reduction for Caregivers.
Philadelphia: Brunner/Mazel, 1999.
- Schonhoff, Shelly & Speaker, Joanna.
Family Caregiver Guide: A Comprehensive Handbook for Caring for Your Loved One at Home.
Dubuque, Iowa: Simon & Kolz Publishing, 1998.
- Unger, James A.
From Caregiver to Caregiver: How to Cope.
Lima, Ohio: CSS Publishing Company, 1995.
- Visiting Nurse Associations of America.
Caregiver's Handbook: A Complete Guide to Home Health Care.
New York: DK Publishing, 1998.

SUPPORT GROUPS & RESOURCES

Washington State Family Caregiver Resource Center:

The Resource Center provides information and other resource materials designed to help unpaid caregivers understand their role and provide better care to their loved one. Materials available include pamphlets and brochures, books, and video tapes.

The Resource Center is located at Pierce County Aging & Long Term Care, 3580 Pacific Avenue - 1st Floor North, in Tacoma. For additional information, contact Senior Information & Assistance at (253) 798-4600.

Washington State Family Caregiver Support Groups

There are a number of support groups especially geared for family caregivers. Support groups serve a worthwhile function, allowing participants the opportunity to ask questions, learn from other's experiences, share successes and frustrations, or seek advice in a safe, supportive environment. Support groups do not charge a fee to participate. Each group is unique, so if one group does not 'feel right,' another may meet your needs. For a current listing of support groups, contact the Senior Information and Assistance program at (253) 798-4600 or 1-800-562-0332, or online at www.pierceseniorinfo.org.

Family Caregiver Support Program (FCSP) Check your state for these programs.

The Family Caregiver Support Program supports unpaid caregivers of older adults and grandparents or relative caregivers of children. Services are free or low cost and generally include:

- information and help getting services;
- caregiver support groups and counseling;
- caregiver training and education; and
- respite care so caregivers can have a break.

Why would you contact them?

Providing unpaid care to a family member or friend can be emotionally and physically draining and can be an isolating time. Staff with the FCSP program can provide information, support, and services that can be a lifesaving resource. Find the [local FCSP](#).

WEBSITES OF INTEREST & NATIONAL ORGANIZATIONS

The National Family Caregivers Association

A caregiver membership organization, provides services in the areas of information and education, support, public awareness and advocacy for caregivers. 1-800-896-3650

Website: <http://www.nfcacares.org/>

Family Caregiver Alliance

The Family Caregiver Alliance is a nonprofit organization that addresses the needs of families and friends providing long-term care at home. The Caregiver Alliance has developed a wide array of services based on consumer needs and is often described as a "one-stop" shopping center for caregivers.

Website: <http://www.caregiver.org>

Family Caregiver Alliance (FCA)

State-to- State Resources

http://www.caregiver.org/caregiver/jsp/content_node.jsp?nodeid=1272

National Alliance for Caregiving

The National Alliance for Caregiving conducts research, develops national projects, and increases public awareness of important family caregiving issues.

Website: <http://www.caregiving.org>

Take Care of Yourself

Caring for another person is the most difficult responsibility you will ever have. While many rewards come with caregiving, there are sacrifices, and demands may be high. Because caregiving can be overwhelming, it's important to pace yourself. It's often difficult to know how long you'll need to provide care, or if your job will become more demanding over time. This job doesn't come with a job description! Caring for your own needs is as important as taking care of the other person. If you are sick, or if you become physically or mentally exhausted, you can't care for someone else.

Common feelings

It's normal for caregivers to **feel sad or discouraged** from time to time. Ignoring these feelings won't make them go away; it may even make them grow stronger. If you feel sad include some pleasant activities in your daily schedule. It can lift your spirits to listen to favorite music, spend a few moments enjoying the garden, or talk on the phone with a supportive friend. If you feel discouraged, take one day at a time. Try to stay flexible and accept the things you can't change.

If you **feel afraid**, talk to someone about the worst thing that could happen and plan what you would do. Planning for the future will help reduce your fears about the "what ifs?"

If you **feel angry** Take a break and leave the situation if possible. A quick walk can help defuse your feelings. If you can't leave, stop and take a few deep deliberate breaths. It really does help! Focus your anger on the condition, not the person you care for. What can you do?

If you feel guilty

Give yourself credit for what you do well. Be realistic about what's possible and what isn't. Focus on one thing you want to do better and be specific. "If only I could make her eat" won't be as helpful as "I will slow down and make mealtimes more pleasant."

Finally, take care of yourself

Talk to someone who can help you look at things more objectively, perhaps a friend, a fellow caregiver, or a professional counselor. Keep yourself physically and mentally healthy Make sure you eat a healthy diet and get some form of exercise as often as possible. A brisk walk is a sure way to relieve stress. Be honest with friends and family about your needs.

Take a break. Schedule time away on a regular basis. To maintain your own emotional and physical health it is absolutely necessary to get relief from your caregiving role.

Get enough rest. If the person is awake at night and it's impossible for you to get a full night's sleep, you may need to consider in-home help during the night or an overnight respite stay (see page 7 on respite programs). Lack of sleep for the caregiver is one of the most common reasons someone enters a nursing home.

Eat well. A good diet will give you more energy. Even one diet improvement can make a big difference over a year's time.

Protect yourself against infection. Wear disposable latex gloves if you will have contact with a body fluid.

Be kind to yourself. Give yourself credit for the things you do well. Treat yourself to a small present when you're feeling low. Take time for a long, hot bath.

Exercise. In as little as 10 minutes a day, and as few as three days a week, the right exercise will help you feel better, sleep better, reduce stress, and enjoy life more for you. Lose weight! Feel good! Sleep better! Prevent osteoporosis! Prevent heart disease! Some general guidelines when you exercise:

- Set aside a specific time every day for exercise.
- Be consistent. To get benefits from any exercise program, do it regularly.
- Warm up and cool down; stretch both before and after you exercise.
- Start with as little as 10 minutes of exercise a day and increase gradually to 30 minutes for maximum benefits.
- Use the talk/sing test. Find out if you're exercising hard enough or not enough, use this simple check. If you can't talk and exercise at the same time, you're working too hard. If you can sing and exercise, you're not working hard enough.
- Always ease into an activity for the first five minutes, and slow down the pace for the last five minutes instead of stopping suddenly.

Exercise ideas: Always check with your doctor before starting any exercise program.

- Take a daily walk. Or DANCE...DANCE...DANCE!
- Find a friend to walk with. You will encourage each other when you're tempted to take a day off.
- Try an exercise video. Look for videos for beginners. Avoid starting with programs that include jumping and twisting. Try videos for stretching, muscle toning, or relaxation. A note of caution
- Check out exercise classes offered through community centers, gyms and senior centers. Look into yoga, tai chi or other non-traditional exercise programs. Call your community swimming pools about adult swim times or water exercise classes.