

# Self-Care for MS Caregivers

The foundation of care giving is self-care for the caregiver.



Making yourself a first priority isn't about selfishness, it's about survival. If you get sick, you are unavailable to care for your loved one.

# Facts and Stats

- About half of all caregivers experience clinical depression; a serious illness that requires medical treatment.
- Caregivers report that they: are sleep deprived, have poor eating habits, get little or no exercise, and postpone or miss their own medical appointments.
- Caregivers with full-time jobs are more prone to weight gain or loss, anxiety, depression, and headaches.

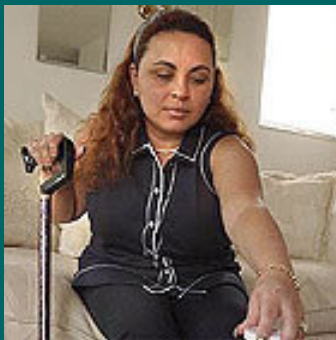


# Summary

- ◆ Care for yourself before you take care of others.
- ◆ Caring for someone can be the most profound and rewarding experience you'll ever have.
- ◆ Self-care for the MS Caregiver, including stress management, is the foundation of care giving.

# Choose to know about MS

- Relapsing-Remitting
- Primary Progressive
- Secondary Progressive
- Progressive-relapsing MS



# Different Types of MS

- Relapsing-remitting MS

- clearly defined attacks (relapses) followed by complete or partial recovery (remissions); **most common form** (75% at time of diagnosis).

- Primary-progressive MS

- continuous worsening of symptoms from beginning usually without clear relapses or remissions; **less common form** (10-15% at time of diagnosis).

- Secondary-progressive MS

- about half of people with relapsing-remitting MS start to worsen within 10 years of diagnosis, often with increasing levels of disability.

- Progressive-relapsing MS

- combines relapses with steady worsening from the onset of the disease; **relatively rare.**

# The Greatest Risk

The greatest risk most MS Caregivers face is BURNOUT:

- BURNOUT IS: depletion of a person's physical, emotional, and spiritual energy.
- BURNOUT AFFECTS: a person's health, mood, attitude, and motivation.

Care giving itself does NOT cause illness, depression, or burnout:

- Stress associated with care giving can cause problems
- Stress in itself isn't harmful; it's chronic stress that's dangerous

Chronic stress can be managed:

- Health problems associated with care giver stress can be prevented
- KNOW the SIGNS and CAUSES of care giver stress and burnout and AVOID it!

# Signs of Caregiver Stress and Burnout

## Physical signs:

- chronic pain, headaches, increased illness, tight muscles especially in neck, shoulders, and back, insomnia, upset stomach, eating junk food, not exercising, weight gain or loss, increase in use of alcohol or drugs, and constant fatigue or exhaustion.

## Emotions/Feelings:

- mood swings, crying a lot, inability to relax, confusion, not taking care of physical appearance, having trouble making decisions, having trouble saying no, feeling worried, nervous, or anxious, feeling sad or empty, feeling trapped, feeling overwhelmed, feeling that care giving is not rewarding, feeling like you're about to collapse or explode, wondering how you can possibly go on.

# Causes of Caregiver Stress and Burnout

## Identify factors affecting you:

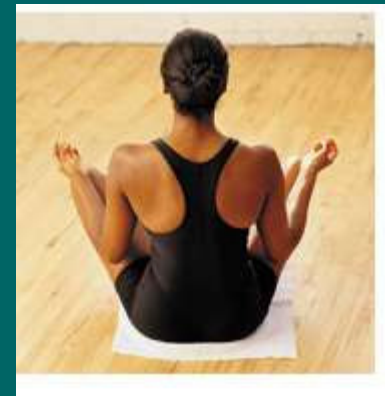
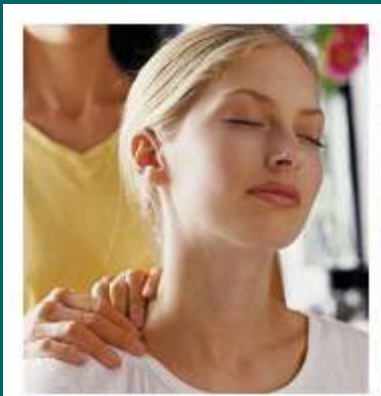
- Are you hoping that care giving will heal the relationship you have with the person you are caring for? You may feel discouraged or resentful if this does not happen.

## What is your care giving situation like?

- Some situations are more stressful than others. Are you caring for someone with cognitive and/or physical disabilities? Do you believe you had a choice about becoming a caregiver? If not, you may feel resentful or trapped. What's your personality like? Are you a perfectionist? Is it OK for you to ask for help?

# Avoiding Caregiver Stress and Burnout

- Take care of YOU!
- You are NOT alone in the care giving process.



# Summary

- Gather basic facts about MS in general and the type of MS your loved one has.
- If you feel you're not in control of your situation, you may be at risk for burnout.
- Everyone tolerates stress differently.
- No one expects you to do everything.
- The key to avoiding caregiver stress and burnout is taking care of you.

# Guidelines for Caregiver Self-Care

- Self-care should make you feel relaxed, re-charged, and in control

# Tips for Self-Care

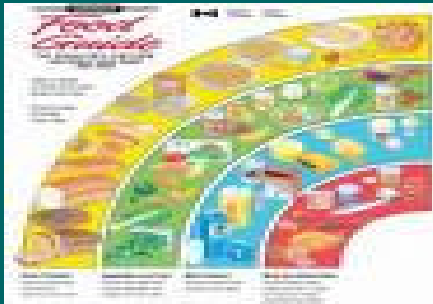
- Try to prepare meals in advance; don't cook every day; enjoy cold nutritious snacks.
- Avoid or reduce caffeinated drinks and sweets.
- Get moving! Take the stairs, walk when you can.
- Try relaxation techniques.
- Pamper yourself: listen to music, read, visit with friends, pray or meditate.
- Let other people nurture you.
- Get practical support from friends and family.
- Tell yourself every day that you are doing a great job.
- Encourage the person you are caring for to actively participate in the care giving process, where possible.
- Give the person you are caring for a break! They need their personal space too!

# Tips for Managing Stress

1. Create a team of caregivers.
2. Get organized by using: charts, schedules, calendars.
3. Ask for help!
4. Keep track of who's doing what, and their contact info.
5. Have 1 primary caregiver.
6. Plan ahead. Perhaps have meetings.
7. Make time for yourself.
8. Delegate chores according to individual preferences and/or share chores.
9. Communicate conflicts, feelings.
10. Avoid isolation: Schedule social time with others; go out on social outings with the person you are caring for, if possible, encourage family and friends to visit you and the person you are caring for, if possible.

# Summary

Make healthy food choices,  
stay active,  
and look after your emotional  
and spiritual self.



Manage stress:  
Stay organized!

August 2005						
Sunday	Monday	Tuesday	Wednesday	Thursday	Friday	Saturday
	1	2	3	4	5	6
7	8	9	10	11	12	13
14	15	16	17	18	19	20
21	22	23	24	25	26	27
28	29	30	31			

Socialize!



Laugh!

Celebrate your achievements.  
Acknowledge your stress.

Get help:  
Don't try to do everything.  
**KNOW YOUR LIMITS!**

# MS Caregiver Needs

- 1.) The more help you get with non-care giving tasks (cooking, cleaning), the more time and energy you will have for the person you are caring for.
- 2) Remember, you can change your priorities and your approach to care giving. Nothing is written in stone.
- 3.) Get practical support: Getting help keeps you connected with others.
- 4.) Look at yourself as a WHOLE person. Care giving is only one aspect of your life.



# Roles and Responsibilities

## The Person living with MS: Roles and Responsibilities

- 1) The person that you are caring for may be able to do much more than you realize.
- 2) Encourage the person you are caring for to take an active role in their care, as much as possible.
- 3) Help the person you are caring for to find new ways to fulfill old roles, as much as possible.

# Roles and Responsibilities continued

## The Primary Caregiver's Roles and Responsibilities, in some cases are . . .

- Basic physical care
- Basic medical care
- Communicating with health care providers to arrange for professional care giving
- Primary contact and organizer for all caregivers
- Responding to emergencies

## Other MS Caregivers may be responsible for . . .

- Taking care of the children of the person you are caring for
- Offering companionship, and transportation to doctor appointments
- Shopper for groceries, and making meals
- Cleaning and laundry
- Out of Towner's: can call, send letters, cards, gifts/keepsakes, pictures, etc . . .

# IMPORTANT

## Caregiver Guidelines

1. Care, comfort, and dignity are top priority!
2. Respect the privacy of the person you are caring for and their family.

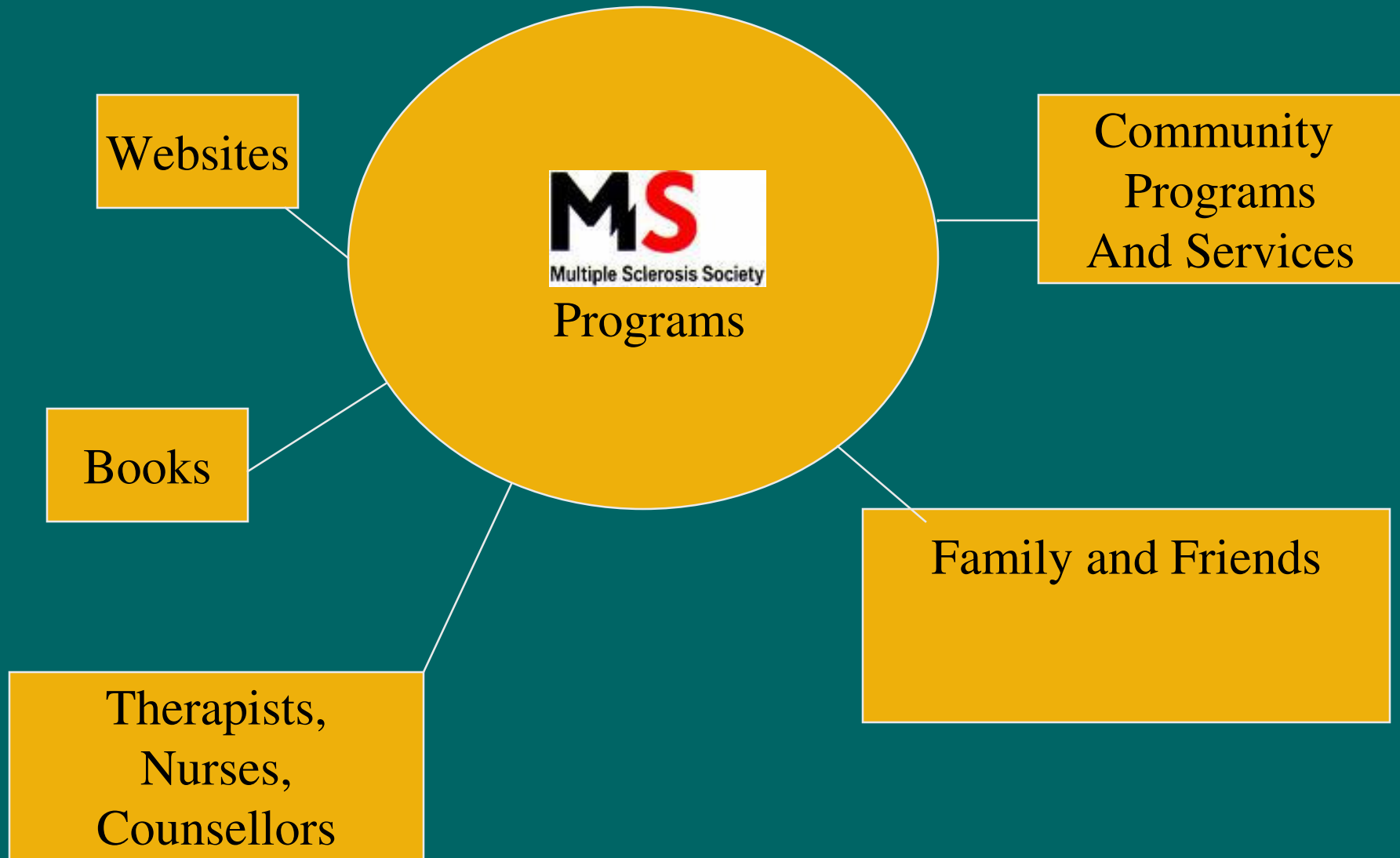
### One last note on Roles and Responsibilities:

- One person may take on several roles, and
- Several people may share the same role

# Summary

- ◆ Understand the roles of the caregivers involved.
- ◆ Know your limits as a caregiver.
- ◆ Understand the needs of the person you are caring for.
- ◆ As much as possible, involve the person you are caring for in the planning of who will provide care, and how.

# Resources



# MYTHS about Self-Care

- **Self-care means time away from your friends or family.**  
**self-care can occur with or without a friend or family member present**
- **Self-care takes a lot of time.**  
**meditation can take only minutes, but the effect can last all day**
- **Self-care is something you must learn to do.**  
**what brings you enjoyment or relaxation is unique to you.**  
**Do what works for you.**



## CONCLUSION:

Take care of  
you!

# About the Presenter

- ◆ Deborah DeCairos Grandmaitre, M.Ed., CCC, a native of Montreal, is a Canadian Certified Counsellor. She works at the Ottawa Hospital and in private practice. Her areas of specialization are: counselling individuals living with MS, disordered eating, and Self-Care for Caregivers. She also enjoys facilitating support groups and workshops. Deborah is close to completing the first of three workbooks, entitled: Self-Care for Caregivers. For more information visit her website: [www.travellerandcompanion.com](http://www.travellerandcompanion.com)