

***Caregivers
The Essential Ingredient***

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I. A Caregiver:

- A person who provides direct care (as for children or chronically ill)
- One who has primary responsibility for a child, parent, or other individual

- Assumed role
 - No instruction manual
 - Round-the-clock shifts
 - Responsible for virtually all needs
 - Typically a family member

 - More than half suffer from symptoms of depression (*women greater than men*)
 - Physical symptoms include back pain, headaches, stomach disorders...
 - Loss of sleep and anxiety common
 - Caregiver stress is inversely correlated to income
- National Family Caregivers Association Survey 1997***

II. Spousal Caregiving:

- “In sickness and in health”
- Sense of inequality, loss of partnership
- Loss of intimacy
- Finances
- Unresolved issues and guilt
- Death denying culture

III. Perceptions of Distress

- Patients and caregivers *each* overestimated the psychosocial impact of the disease on the other.
- Burdened caregivers tend to rate patients as suffering more than less burdened caregivers
- Patient perceptions of caregiver burden were related to their understanding of care demands and caregiver reactions

Adelman EE et al. Neurology 2004; 62(10):1766-1770

IV. **“Burden” in ALS**

- Caregivers perception of burden increased with worsening of the patients disability (i.e. declining ALSFRS score)
- Patients cognitive functioning is an important factor in determining level of burden
- To ensure optimal care of PALS, caregiver’s burden must be reduced as much as possible

Chio et al. Neurology 2004; 64:1780-1782

V. **Caregiver Checklist**

- What is changing?
- What bothers me about this change?
- What must be dealt with now, and what can wait until later?
- What has not changed?
- How can I make this better, or at least not as bad?

VI. **Home Care Information Sheet**

- Patient’s name and vital statistics
- Medications and physician information
- Task schedules
- Names of vendors and suppliers

VII. **Caregiving:**

The Spiritual Journey of Loss, Love and Renewal

By Beth Witrogen Mcleod

VIII. **The Inner Journey**

- Typically more emotional than physical
- Each juncture of the journey offers choice
- Each stage of life holds the seeds for our spiritual growth
- Open your hearts to live fully in the midst of great loss

IX. **Acceptance**

Accept that you may need help from others, including family, friends, neighbors, community programs, medical societies, and religious and fraternal groups.

X. **Communication**

- Talk regularly with family, friends, or mental health professionals.

- Find a support group, locally or on the internet, so you can share your feelings before they escalate into problems.
- Discuss changes in relationships

XI. **Set Limits**

It's alright to say "no" to taking on more than you can handle - both physically and emotionally

XII. **Self Care**

- Eat nutritiously
- Set aside time each day for yourself
- Exercise regularly
- Get enough sleep
- Take time to laugh, sing, stretch and sigh...

XIII. **Self Care (cont.)**

- "Why Zebras Don't Get Ulcers", Robert Sapolsky PhD
 - Stress and the immune system
 - Stress and memory
- Stress reduction
 - Offer up a platter of choices
 - Just say no to multi-tasking

XIV. **A Deep Minute**

- Find a comfortable position and let your eyes close
- Breathe slowly, deeply and evenly. Feel each breath come in and out
- Visualize a calm and relaxing place that nourishes your sense of comfort
- Feel the cool breeze brushing over your body, blowing away your stress and anxiety
- Reopen your eyes in control, ready to move forward

XV. **Managing Emotions**

- Let go of unrealistic expectations and demands
- Identify and admit to fear, anger and guilt
- Try not to become a martyr
- Establish distance from the intensity of the situation

XVI. **Rewards of Caregiving**

- An enriched understanding of relationships and family
- Review of lessons learned

- Sense of fulfillment and personal growth
- Knowledge that you have persevered and not been conquered by the odds

XVII. **Conclusions**

Every day gives abundant opportunity to decide whether to be a victim or embrace the world

XVIII. **Resources**

- Family Caregiver Alliance
 - (415) 434-3388; www.caregiver.org
- Caregivers.com
 - (608) 256-0488; www.caregivers.com
 - Empowering Caregivers
- ALS Support Groups
 - www.alsa.org go to "in your community"