Caregiving: Providing Care while Managing Stress

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Not everyone will be healthy in old age, so How do we cope when challenged with age-related decline?
There are four kinds of people in the world. Those who
- have been caregivers,
- are currently caregivers,
- will be caregivers,
- will need caregivers.

Rosalynn Carter
Caregiving plays a unique and valuable role in our society. As the number of caregivers grows, the issues surrounding caregiving have gained national attention from a variety of sectors... National adoption of public health priorities is guided by specific principles (Rao, Anderson, & Smith, 2002).

These principles include large burden, major impact with respect to health costs or consequences, and potential for prevention.

CDC’s Assuring Healthy Caregivers (2008).
In 2009, 42.1 million Americans provided unpaid care to another adult with ADL limitations at any given point; 61.6 million at some time in the year.

Economic value of unpaid contributions = $450 billion. *(Walmart sales = $416 billion in 2011)*

Without this “informal” workforce, the entire health care and LTSS system would be in jeopardy.

Feinberg et al., 2011
Caregiving is Beyond the Critical Tipping Point

- Family caregivers must...
  - Care for patients discharged “sicker and quicker”
  - Navigate health care systems lacking coordination
  - Deal with “information overload”
  - Manage difficult medication schedules and sophisticated technology at home
  - Juggle competing demands (e.g., work and care)
  - Locate, access, and monitor quality paid help
  - Care sometimes at a distance

Feinberg; Schmall
Caregiver - The Hidden Patient

**AT RISK FOR:**

- Depression
- Extreme fatigue, stress, anger/ frustration
- Anxiety, upset, feeling overwhelmed
- Guilt
- Financial loss
- Social isolation
- Physical health problems/Morbidity
- Mortality (?)

Coon et al., 2003; Ory et al., 1999; Schulz et al., 1995; Schulz & Beach, 1999; Vitaliano et al., 2003
All I ever needed to know…
I learned in kindergarten.

Robert Fulghum
I don’t think Robert Fulghum was a family caregiver.

D.W. Coon
What’s Successful? Implementing Caregiver Interventions

- **Education & Skills Training (CR, CG, both)**
- **Psychotherapy/Counseling (CBT skills)**
- **Multi-component; skills training combined with**
  - Support
  - Education
  - Respite
  - Case management
- **Common threads with mid and later life mood disturbances: cognitive & behavioral skills and practice for behavior change.**

Coon, et al., 2012; Coon & Evans, 2009; Ghaed, Ayers, & Wetherell, 2012; Gallagher-Thompson, & Coon, 2007; Scogin & Shah, 2012; Thompson et al., 2010.
A Case Study with
DOING TOOLS
Strategies Caregiver Can Use to Prevent the Problem Behavior

1. Set out fresh clothes for him and reward him when he wears them; give him a compliment on how nice he looks or make him his favorite breakfast.

2. Hide the outfit he really likes where he cannot find it.

3. Buy him several pairs of the same pants and shirt so that he thinks he is wearing his favorite outfit.

4. When he goes to bed, take his clothes and put them in the laundry machine. Set the machine on the soak cycle so that if he looks for them and notices they are wet, he will need to find something else to wear.
And now with THINKING TOOLS
Self Talk Mood Management

- Learn new forms of “self-talk” to encourage yourself throughout the day.

- Three steps to managing your feelings:
  1. Stop and identify current thoughts.
  2. Challenge & replace unhelpful thoughts.
  3. Pay attention to how you feel.
CARE VALUES

INDEPENDENCE
- Do things for self
- Come/go as you please
- Organize daily routines in your own way
- Spend money how you want
- Have something to do
- Have time for self
- Make own financial decisions

ACTIVITIES WITH OTHERS
- Do things with others
- Be with family/friends
- Be part of family celebrations
- Keep in touch with the past
- Keep in touch with distant family and friends

WHO HELPS OUT
- Keep the same doctor
- Choose the family who helps
- Have reliable help
- Choose who is excluded from helping you

REDUCING FAMILY STRESS
- Reducing your family’s or friends’ worries, concerns and how to cope with physical demands, emotional strain, and financial impact related to your care.
- That CP not put his/her life on hold for you
- Have money to leave the family

SAFETY
- Feel safe inside the home
- Be in touch with others in an emergency
- Be safe from crime

Reamy et al, 2011
CARE TASKS

Self
- Cooking
- Toileting
- Housework
- Getting in and out of bed
- Taking medication
- Driving/transportation
- Eating
- Financial/legal matters
- When I feel restless/bored
- Laundry
- Doing things I enjoy
- Dressing/undressing
- Making doctor’s appointments
- Shopping for food

To be with me when outside of the house
To be with me during the day
Help during the night

Family & Friends

Paid Helper
CARE TASKS

SELF
- COOKING
- SHOPPING FOR FOOD
- HELP DURING THE NIGHT
- TAKING MEDICINE
- EATING
- MAKING DOCTOR'S APPOINTMENTS
- GETTING IN AND OUT OF BED

PAID HELPER
- BATHING/SHOWERING
- DRIVING/TRANSPORTATION
- LAUNDRY
- HOUSEWORK

FAMILY & FRIENDS
- TO BE WITH ME WHEN OUTSIDE OF THE HOUSE
- TO BE WITH ME DURING THE DAY
- WHEN I FEEL RESTLESS/BORED
- FINANCIAL/LEGAL MATTERS

DOING THINGS I ENJOY
DOING TOOLS
### Four Pleasant Events a Day: Helps Keep the Blues Away

<table>
<thead>
<tr>
<th>Pleasant Events</th>
<th>Days</th>
</tr>
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<tbody>
<tr>
<td></td>
<td>1</td>
</tr>
<tr>
<td>1. Working on Computer</td>
<td>✔</td>
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<tr>
<td>2. Reading Religious Books</td>
<td>✔</td>
</tr>
<tr>
<td>3. Attending a Good Movie</td>
<td></td>
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<tr>
<td>4. Going for Walks</td>
<td>✔</td>
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<tr>
<td>5. Browsing in Library</td>
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<tr>
<td>6. Listening to <em>Car-Talk</em></td>
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<tr>
<td>7. Listening to Music</td>
<td>✔</td>
</tr>
<tr>
<td>8. Yoga</td>
<td>✔</td>
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<tr>
<td>9. Meeting with Friends</td>
<td>✔</td>
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<tr>
<td>10. Getting out for a Drive</td>
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<tr>
<td><strong>Total</strong></td>
<td>5</td>
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</tbody>
</table>
Social Support & Effective Communication

*We get by with a little help from our friends....*

- Or in spite of ...?
But....

Is all social support good?
AVOID TOXICS!!!
Communication Skills

◆ Good assertive communication:
  ▪ Identifies the situation.
  ▪ Describes what you think & feel.
  ▪ Expresses what you want the listener to do & what you can do in return.
  ▪ Assert why the “ask” and how it can help.
  ▪ Listen carefully to the response. Negotiate as needed.

◆ People have the right to say “No.”.
Stress MGT: Mindful Breathing

- Body & Mind Scan
- Choose a word that represents relaxation for you
  - (peace, relax, calm)
- Four deep breaths; mouth your word during exhale
- Rate tension (before & after)
- Practice!
- Alternative:
  - Tense muscles on inhale and release while mouthing your word.
Skills for Life

Doing Tools
- Pleasant Events
- Problem Solving & Behavior Management
- Assertive Communication & Rallying Support
- Relaxation Strategies

Thinking Tools
- Self-Talk: Managing Unhelpful Thinking
- Values Clarification & Care Task Preferences
- Positive Affirmation
Take time to take care of yourself is the BEST GIFT you can give to the person who needs your care.
Concluding Comments

- The truly strong in our society are those who reach out for support, whether the abscess is on the knee or on the soul.

- **Courage** is the willingness to face the unexpected, for that is what defines it.

- Individuals facing chronic illness or impairment and their caregivers are incredibly courageous.