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# Support Group for Spouse/Partners of Mentally Ill Spouses/Partners

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## **Week One**

### **Welcome and Group Rules/Norms**

#### **Learning Objectives:**

- To engage participants in creating group rules and norms
- To begin to examine the impact of living with a mentally ill partner.
- Discussion points: Support group norms, getting to know each other.

Prior to group:

- Post the group rules and norms on the wall where they can be seen by the group.
- Have listed supplies

#### **Materials:**

- **Clip boards/ writing board**
- **Name tags**
- **Pre/post survey**
- **Flip chart/white board**
- **Markers**
- **Pens/pencils**
- **Thought handout (addendum C)**
- **Burn-out signs (addendum O )**
- **Ensuring confidentiality (addendum D)**

## Outline:

1. Sign in, introductions and Checking in (10-15 minutes)
  - a. As participants arrive give each, pen/pencil, clip board and pre/post survey. Ask participants to fill out the survey and then return it to the facilitator. Place these face down and ensure confidentiality.
  - b. Introduction: Each facilitator and participant should introduce themselves. Check – in question: What is goal in attending this support group?
    - i. The purpose is to create group cohesion, creating common bonds and creating a safe, welcoming environment.
2. Develop Group Rules/Norms/Expectations (10-15 minutes)
  - a. Ask the group to list group agreements, norms and rules
    - i. See addendum B for an example of group norms and rules
    - ii. As facilitator be prepared to guide and lead the conversation.
    - iii. As facilitator ensure the group of the standards of confidentiality. Addendum C: lists the facilitator’s roles in insuring group confidentiality regarding the organizations role in keeping any information private and confidential. This list need not be shared with the group, but is a point of reference for the leader.
  - b. Write down the group rule/norms on the flip board; be prepared to post these at each group.

- i. Once group norms have been established ensure that the group members agree with them and make any changes as needed.
3. Complete the “Thought handout” addendum C. (20-30 minutes)
  - a. Encourage each person to share their answers
    - i. Each participant is welcome to pass
  - b. This is an opportunity for the group members to connect, do not be afraid to let silences happen.
4. Closing (10 minutes)
  - a. Ask if there are any questions about the direction of the group?
  - b. Closing thoughts from any members
  - c. Closing quote: “Do more than belong: participate. Do more than care: help. Do more than believe: practice. Do more than be fair: be kind. Do more than forgive: forget. Do more than dream: work.” William Arthur Ward
  - d. Handout

## Week Two

### Intimacy

#### Learning objective:

- To engage participants in discussion surrounding changes in intimacy
- Assist group in generating thoughts and ideas to reduce the barriers they face and create solutions.

#### Prior to Group:

- Have listed supplies
- Post group norms and rules developed from week one

#### Materials:

- **Nametags**
- **Clipboards**
- **Blank paper**
- **Pens/pencils**
- **Timeline handout: Addendum E**
- **Intimacy scale: Addendum F**
- **Sign in sheet**

#### Outline:

1. Welcome, Sign in and Check in (5-10 minutes)
  - a. As participants arrive give each a name tag, clip board and pen/pencil

2. Introduction: Each facilitator and group member should introduce themselves
  - a. Check in question: How did your week go? How do you feel after the last meeting?
  - b. Review group norms and rules.
3. Introduce discussion topics for group: (2 minutes)
  - a. Hand out addendum E: **Illness time line (20 minutes)**
    - i. Explain time line. On the top of the time line create time line of major life events since the beginning of relationship. On the bottom of the time line document the trajectory of the illness, noting any major milestones, barriers or important events reflected by the illness.
  - b. Discussion: What does the timeline mean to you? How does it impact your life? How did it change your perspective on what you *expected* your relationship to be?
    - i. Allow for discussion- assist the group in recognizing commonalties and difference.
4. Hand out the **Intimacy: Before and After** Addendum F (25 minutes)
  - a. Allow time for group to complete the handout (5-10 minutes)
    - i. Discussion question: What did you recognize about changes in your intimacy?
      1. How do those changes impact you?
5. Closing: (10 minutes)
  - a. Quote: “Intimacy is the capacity to be rather weird with someone - and finding that that's ok with them.” – Alain de Botton
    - i. What is one thing you might try to improve your intimacy with your partner?

## **Week Three**

### **Roles**

#### **Learning Objectives:**

- To engage participants in recognizing household roles and their impact to the relationship.
- Acknowledging the strength it required to be accepting to a balance discrepancy in household chores, while maintaining your own current roles.

Prior to group:

- Post the group rules and norms on the wall where they can be seen by the group.
- Have listed supplies

#### **Materials:**

- **Name Tags**
- **Clip board or writing board**
- **Group norms to post on wall**
- **Pens/Pencil**
- **Addendum H**

## Outline:

1. Sign in- checking in (10-15 minutes)
  - a. Acknowledge and point to where the rules are posted- this need not be formal, but just a reminder as the group begins to acknowledge the group agreements.
  - b. Opening question: How have you been this week? Any wins that anyone would like to report areas of struggles?
2. Introduce roles and what they are- father, mother, sister, daughter, wife, husband ect
  - a. **Activity** Addendum H (40 minutes)
    - i. You only need one copy for the facilitator of this activity
    - ii. After completion of activity ask the following leading questions
      1. Does anyone want to share their feelings?
      2. What are you doing to adapt to these role changes?
      3. What has been the greatest source of frustration regarding the issues of roles?
      4. If you could name one tip to cope with these changes what would it be?
      5. What has been the greatest impact to the family due to the role changes? Have you seen changes in the family dynamic?

**Closing quote:** When things fall apart, consider the possibility that life knocked it down on purpose. Not to bully you, or to punish you, but to prompt you to build something that better suits your personality and your purpose. Sometimes things fall apart so better things can fall together.



## Week Four

### Tough conversations

#### Learning objectives-

- To engage participants in learning how to have tough conversations with loved one
- To learn one technique of how to phrase conversations that helps mitigate defense mechanisms.

Prior to group:

- Post the group rules and norms on the wall where they can be seen by the group.
- Have listed supplies

#### Materials:

- **Clipboards/writing boards**
- **Name tags**
- **Group norms/rules**
- **Pens/pencils**
- **Addendum I**
- **Paper strips- enough for everyone in the group to have one. Large enough to write a sentence or two on it**
- **Basket or some other container**

## **Outline:**

1. Sign in, name tags, checking in (10-15)
  - a. Ask: Are you more aware of the roles you play in the house and how that has changed since the mental health diagnosis?
2. Introduce tonight's topic of "having tough conversations"
  - a. **Ask:** What is a technique that has worked for you in the past?
  - b. **Ask:** What happens when conversations go wrong?
    - i. Validate and allow for discussion about the frustrations of trying to bring up difficult topics that may be hurtful to the spouse/partner.
      1. **Ask:** What happens when a conversation escalates?
        - a. Some answers might include: defense mechanisms trigger, conversation turns to argument, feelings of guilt, anger, sadness.
      2. **State:** "Tonight we are going to work on one skill to have tough conversations that allow us to state our emotions and feelings in a way that does not overtake the conversation- perhaps leading to an argument or the conversation going south.
3. Hand out Addendum I (20-30 minutes)
  - a. Explain the concepts surrounding this technique: This is one tool that you can use to help center your thoughts, and present your concerns in a kind, loving way- but takes some of the emotional baggage out of it.

1. Complete the handout: Ask the group to take 10 to 15 minutes to fill out the form about an issue they have wanted to speak to their spouse about.
  - a. Share- Ask the group if anyone is willing to share what they have written. Explain that by sharing that we may find in the group that we all have the desire, need or necessity to have this difficult conversation with their loved one.
  
4. **Closing** (10 minutes) - What was one take away from tonight's group? Are there future topics that you may like to discuss in the future?
  - a. **Write**- write down any topics they wish to see in future groups. Place this list in the binder in the back- under the tab "Future Topics"

## Week 5

### Stigma/Isolation

#### Learning objectives:

- Teach about stigma and how stigma impacts families
- Acknowledge how stigma causes isolation
- Address stigma in all its forms and how it impacts the mentally ill spouse, but the family as well.

Prior to group:

- Post the group rules and norms on the wall where they can be seen by the group.
- Have listed supplies

Materials:

- **Clip boards/writing boards**
- **Name tags**
- **Group norms/rules**
- **Pens/pencils**
- **Addendum J- Stigma, copies enough for each group member to have a copy**

## **Outline:**

1. **Sign in and Checking in** ( 10 minutes)
  - a. **State:** Last week we discussed about having tough discussions- what are your thoughts about that now that you've had some time to process?
2. **Introduce this week's topic:** This week we are going to discuss stigma and its impacts on your loved one, but also how it affects your life as a family member and caregiver.
  - a. **Handout Addendum J**
    - i. **State:** Please take a few minutes to read this article. It will help shape our conversation about stigma.
3. **Discussion:** (40 minutes)
  - a. **Ask:** The following questions for conversations
    - i. What does stigma mean to you?
    - ii. How has stigma affected your family? (possible answers may include embarrassment, delay in seeking services, changes in work, isolation, decrease in self-esteem)
    - iii. How do you think stigma is perpetrated?
    - iv. So often the focus is on the mentally ill person, and the caregiver is largely ignored as the caretaker/spouse/partner how has stigma directly affected you?
4. **Closing:** (10 minutes)
  - a. **State:** Today we've had a discussion about Stigma- this week what is one thing you can do to reduce stigma? (Answers may include- pay more attention to the

media portrayal, be more aware of what your spouse/partner faces regarding being stigmatized.)

## Week Six

### “Secrets you wish you could share”

#### Learning objectives:

- To engage participants in exploring feelings of their own grief.
- Ways which grief/isolation/stigma affect the caregiver
- Help caregiver name and own the negative aspects of being a caregiver

Prior to group:

- Have listed supplies
- Post group norms and rules developed from week one
- As participants arrive give each a name tag, clip board and pen/pencil, and piece of paper

#### Materials

- **Clip boards/writing boards**
- **Name tags**
- **Group norms/rules**
- **Pens/pencils**
- **Strips of paper- enough for each participant to have 2-3**
- **Paper**
- **Basket hold paper strips**

## **Outline:**

### **1. Sign in and Checking in ( 5 minutes)**

- a. This week we are going to acknowledging some of the silent sides of being a care giver to your spouse/partner.
- b. “Let’s take a minute to review the norms and rules of the group” (this week’s topic may be difficult to stop the “advice givers” so reviewing will help put appropriate behavior in the forefront.)

### **2. Ice-breaker (15 minutes):**

- a. Give each person a piece of paper
- b. Ask them to write two truths and one lie
- c. Go around the group and see if the group members can figure out what are the truths and what the lie is.

### **3. Introduce tonight’s topic: (30-40 minutes) “Secrets you wish you could share”**

- a. Give each participant two strips of paper- on the paper they should write anonymously, a secret they wish they could share about being a caregiver. After they are done they place the papers in the basket.
  - i. Pass the basket and have each participant take one of the slips of paper.
  - ii. Go around the group having each participant read what is on the paper-
    1. ASK: “Does this secret resonate with any of you?” Invite discussion- leading the conversation to look for commonalities and difference.

**Closing:** (10 minutes) Do you feel like you have a person in your life that you can talk to about these feelings?



1. Closing quote: “Every man has his secret sorrows which the world knows not; and often times we call a man cold when he is only sad”. – Henry Wadsworth

Longfellow, *Hyperion*

## Week Seven

### Burden/Burnout

#### **Learning Objectives:**

- Teach about types of burden
- Lead discussion about burnout

Prior to group:

- Post the group rules and norms on the wall where they can be seen by the group.
- Have listed supplies

#### Materials

- **Clip boards/writing boards**
- **Name tags**
- **Group norms/rules**
- **Pens/pencils**
- **Paper**
- **Addendum K (burn-out quiz) one for each participant**
- **Addendum L (Burn-out wellness handout)-one for each participant**

## Outline:

### 1. Sign in- checking in (10-15 minutes)

1. Acknowledge and point to where the rules are posted- this need not be formal, but just a reminder as the group begins to acknowledge the group agreements.

i. Opening question: How have you been this week? How did you feel after last group?

### 2. Introduce discussion topics: “Tonight we are going to discuss two issues that you may feel most heavily in your relationship- Burden and burnout”

#### 1. State/Read: “There are two types of burden-Objective and Subjective”

i. Objective: Is the measurable- for instance financial costs and disruptions to the family.

ii. Subjective: is related to the feelings surrounds the ways in which they felt burdened. This is the type of burden that equates to the emotional cost. “In their article, *Mastery, Burden and Areas of Concern among Family Caregivers of Mentally Ill Persons*, Rose, Mallinson, and Gerson (2006), write to the idea that burden is not correlated with the number of hospitalizations. They believe serious mental illness can result in grief for both the person and the family. “The perceived losses may be tangible (e.g., loss of functioning level) or symbolic (such as loss of “hopes, dreams and expectations) and contribute to an unending chronic sorrow characterized by wavering emotions as a result of episodic illness trajectory.” ( p. 42).

2. **Discussion (25-30 minutes)** about topics of burden- you can use the following questions or develop your own.
  - i. “What resonates the most with you?”
  - ii. What kinds of emotional costs have suffered?
3. **Burnout-** handout addendum K
  1. Have each participant fill out the quiz. Explain that this is just an informal tool to help teach what burn out looks like and its signs and symptoms.
    - i. After each person is finished- Ask: Was anything surprising to you? How does this make you feel?
4. **Closing**: What is one thing you can do this week that will help mitigate the depth of your burn out? Hand out Addendum L.

## Week Eight

### Resiliency and Self Care

#### Learn Objectives:

- To engage participants in learning resiliency tools
- Identify emotions that interfere with self care and resiliency
- Wrapping up group and saying good bye

Prior to group:

- Post the group rules and norms on the wall where they can be seen by the group.
- Have listed supplies

#### Materials

- **Clip boards/writing boards**
- **Name tags**
- **Group norms/rules**
- **Pens/pencils**
- **Paper**
- **Addendum M- Resilience Tree –enough for participants**
- **Addendum N –Handout on Resiliency –enough for participants**
- **Large white board or large flip posters**
- **Appropriate Markers**
- **Pre/Post survey- enough for everyone**

## Outline:

1. Sign in, name tags checking in (10 minutes)
  - a. **Ask:** Last week we discussed how to have difficult conversations; did anyone try that technique out? Thoughts?
    - i. Introduce tonight topic: Tonight we are discussing Resiliency and Self Care- why is these important topics?
2. State: Lets take a few minutes and brain storm some habits of resilient people. (10 minutes)  
(Answers may include: positive thinking, able to be uncomfortable with issues in life, able to keep perspective, exercise, practicing self care... )
3. Handout Addendum N (15 minutes)
  - a. State: “Let’s take about 15 minutes to read over this page and then we can discuss which one of these items resonate the most in you.”
4. Handout Addendum M – Resilience Tree (20-25 minutes)
  - a. State: “Take this sheet and fill out the upper arms on what makes you resilient. Take special care to note your most positive attributes, strengths and abilities that you have cultivated in caring for your loved one”
  - b. State: “On the “roots” of the tree- you may need to draw these on, list the marital qualities that have made you and your spouse/partner resilient though these tough times as well as identifying what you do to practice self care.”
    - i. Would anyone like to share a branch or root?
  - c. **Closing:** As we close our group after 8 weeks of being together- I’d like to take a few last minutes and fill out the post survey. I’m especially interested in your ideas of topics you’d like to see in the future.

d. What is the one take away from group that has affected you the most?

## **List of Addendums**

Addendum A- Initial/Final Survey

Addendum B- Group Agreements

Addendum C- Thought Handout

Addendum E- Our Timeline

Addendum F- Intimacy-Before/After

Addendum H- Role changes in the family

Addendum I- Difficult conversations

Addendum J- Coping with Stigma (2 pages)

Addendum K- Burnout Quiz (3 pages)

Addendum L-Burnout Wellness (2 pages)

Addendum M- Resilience Tree

Addendum N –Resilience: A helpful tool for caregivers (2 pages)

Addendum O- Caregiver stress (2 pages)



Addendum A

Date \_\_\_\_\_

Name \_\_\_\_\_

Initial/Final (circle one)

Please answer the following on a scale of 1 to 5: One being none and five being fully understood.

1.) Do you feel you understand your partners/spouse mental health condition? Meets criteria 1B

1                      2                      3                      4                      5

2.) How well do you understand his/her mental health symptoms? Meets criteria 1A

1                      2                      3                      4                      5

3.) I feel like I am able to communicate with my spouse about my feelings regarding the mental health diagnosis? Meets criteria 2A

1                      2                      3                      4                      5

4.) I feel like I have the tools needed to keep my relationship stable and strong? Meets criteria 2B

1                      2                      3                      4                      5

Any comments or hopes for what you will learn in the group?

**Support Group Ground Rules**

1. Each situation is unique. While you may share some commonalities in your experiences, no two of you are exactly alike. Consequently, respect and accept both what you share in common with others in the group and what is unique to you.
2. Expressing and Listening are different. Actively listening is as important for our group as is expressing your own feelings of loss. Make every effort not to interrupt when someone else is speaking.
3. Confidentiality. Thoughts, feelings and experiences shared in this group will stay in this group. Do not use the names of fellow participants in discussions outside of this group.
4. Try not to monopolize. Allow each person equal time to express himself or herself. Allow your facilitator to let you know if it is time to let others share.
5. Attend each group meeting and be on time. If you decide to leave the group before the completion of the series of meetings, be willing to discuss your decision with the group.
6. Avoid “advice giving”. If advice is not solicited, don’t give it. If a group member poses a question, share ideas that helped you if you experience a similar situation whenever possible.
7. Thoughts and feelings are neither right nor wrong. Enter into the thoughts and feelings of other group members without trying to change them.
8. Create an atmosphere of willing, invited sharing. Cell phones and other electronics don’t encourage sharing or listening. Please turn them off or on vibrate if needed in case of an emergency.
9. Respect silence. Even if it makes you uncomfortable it is important to give the group a chance to pause and contemplate what they are thinking and feeling. In addition it is important to let everyone feel that it is okay to listen and not talk.

**Activity: Complete the Thought Handout**

Using your own words, completing the thought: For example: "If I could be anyone, I would be \_\_\_\_\_."

1. The thing that concerns me most about joining group's is?
  
2. When I am feeling anxious in a new situation, I usually\_\_\_\_\_.
  
3. When I am new in a group, I\_\_\_\_\_.
  
4. In groups, I feel most comfortable when the leader\_\_\_\_\_.
  
- A. 5 .My greatest hesitation in relating to others in a group is\_\_\_\_\_.
  
- B. 6. What I would like from other members of this group is\_\_\_\_\_.
  
- C. 7. What I am willing to share with members of this group is\_\_\_\_\_.

**Ask for group members to share their answers to each of the thoughts. Go through as many as time permits.**

OUR TIMELINE

ILLNESS TIMELINE



Intimacy -Before /After

**Scale of one to five- Five being ideal**

Sexual Intimacy \_\_\_\_\_ / \_\_\_\_\_

Emotional Intimacy (being tuned in to each other's wavelength)  
\_\_\_\_\_ / \_\_\_\_\_

Intellectual Intimacy (closeness in the world of ideas) \_\_\_\_\_ /  
\_\_\_\_\_

Aesthetic Intimacy (sharing experiences of beauty) \_\_\_\_\_ / \_\_\_\_\_

Creative Intimacy (sharing in acts of creating together)  
\_\_\_\_\_ / \_\_\_\_\_

Recreational Intimacy (relating in experiences of fun and play)  
\_\_\_\_\_ / \_\_\_\_\_

Work Intimacy (closeness of sharing common tasks) \_\_\_\_\_ /  
\_\_\_\_\_

Crisis Intimacy (closeness in coping with problems & pain) \_\_\_\_\_ /  
\_\_\_\_\_

Commitment Intimacy \_\_\_\_\_ / \_\_\_\_\_

Conflict Intimacy (facing and struggling with differences) \_\_\_\_\_ /  
\_\_\_\_\_

Spiritual Intimacy \_\_\_\_\_ / \_\_\_\_\_

## Communication Intimacy \_\_\_\_\_ / \_\_\_\_\_

<http://bettermarriagesga.org/Exercise5.html>

Retrieved from :

### **Role changes in the family**

Addendum H

- Have the group stand in a circle.
- Ask the following question- “Who feels that there have been role changes since the mental illness diagnosis or as a result of the illness?”

Ask the group members to step forward if they find the statement to be true that they have noticed changes in:

- Financial responsibilities-
- Paying the bills
- Household chores
- Cooking
- Cleaning
- Child care
- Pet care
- Car care
- Work
- Family relationship
- Social functions
- Any others?

Have the members take their seats.

Recognize role changes-

Ask: Does anyone want to share feelings surrounding role changes? What are you doing to adapt?



Difficult Conversations

Dear \_\_\_\_\_, There are some things I've not been saying to you. I'm not saying them, because I'm afraid the following might happen...

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What I would like/hope to have happen by my telling you is...

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And what I'm not telling you is:

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Thank you for listening. What, if anything, would you like to share in response to this?



Retrieved from : <https://s3.amazonaws.com/free-reid-stuff/Difficult+Conversations/Difficult+Conversation+Worksheet.pdf>  
Full credit is due to <http://www.ouhsc.edu/safeprogram/18CopingWithStigma.pdf>

This is a program developed for Service Families and members and can be fully assessed from the above address.

### **Understanding the history of stigma in mental health**

A. Unfortunately, the mental health profession contributes to the stigma surrounding mental illness. For example, as recently as the 1960s and 70s, mental health professionals were taught that schizophrenia was caused by being raised by a cold, unavailable, critical “schizophrenogenic mother” and living in a family marked by high expressed emotion, which involves much criticism, hostility, and emotional over-involvement. Families were held responsible for the loved one’s mental illness.

B. These theories guided our understanding of mental illness and psychiatric care, and the mental health profession harshly judged many families. Unfortunately, this viewpoint contributed to the stigma and sense of responsibility that many families experienced.

C. Since that time, science has reformulated our theories regarding the cause of mental illness, resulting in a fairly widespread acceptance of the vulnerability/stress model (as explained in session one) of etiology.

1. As a review, the vulnerability-stress model involves understanding mental illness as being caused by a combination of “nature” (genes, heredity, etc.) and “nurture” (family upbringing, life events, social environment, etc.). ?205

2. Individuals may inherit a predisposition to mental illness and then experience a stressor that results in the emergence of an illness. On the other hand, an individual may be born with a predisposition but have excellent coping strategies and/or social support and never experience the illness.

3. Research continues to explore the relative contributions of genetics and life experiences to various mental illnesses. For example, some illnesses (e.g., schizophrenia) are believed to be highly influenced by genetics; while others (e.g., PTSD) are more a response to life events/situations.

D. In spite of science's shift away from a "family-blaming" mentality, many families continue to feel responsible for their loved ones' illnesses. Perhaps in response to this experience and in an attempt to relieve years of guilt, many families and advocacy organizations have adopted an extreme "nature" viewpoint; this perspective conceptualizes mental illnesses as "neurobiological disorders" and minimizes the role of any social/family contribution.

E. Similarly, there is growing attention to means of overcoming stigma evidenced by research, practice recommendations, and reports urging the profession to tackle this challenging topic. For example, the President's New Freedom Commission on Mental Health report, *Achieving the Promise: Transforming Mental Health Care in America*, includes a recommendation to "Advance and implement a national campaign to reduce the stigma of seeking care. In a parallel vein, mental health providers have recognized the role that stigma places in deterring service members from seeking mental health help (both while on active duty and thereafter) (Hoge, Castro, Messer et al., 2004), and many new programs are attempting to make our services more accessible.

Retrieved from: <http://www.ouhsc.edu/safeprogram/18CopingWithStigma.pdf>

## Burnout quiz

**1) I wake up in the morning and dread the day.**

- Almost Always
- Often
- Sometimes
- Never

**2) I am overwhelmed by all the tasks i need to accomplish for the people who count on me.**

- Almost Always
- Often
- Sometimes
- Never

**3) I have health problems of my own that seem to be getting worse (for example, high blood pressure, stomachaches, headaches).**

- Almost Always
- Often
- Sometimes
- Never

**4) I am using alcohol, cigarettes, caffeine, and/or sleeping pills or other medications more than I have in the past.**

- Almost Always
- Often
- Sometimes
- Never

**5) I have put off going to the doctor for my own health issues.**

- Almost Always
- Often
- Sometimes
- Never

**6) It feels like all of my time is spent attending to the needs of others. I have no time to pursue leisure activities that give me pleasure.**

- Almost Always
- Often
- Sometimes
- Never

**7) My thoughts are always about my responsibilities.**

- Almost Always
- Often
- Sometimes
- Never

**8) My sleep patterns have changed (I now sleep fitfully, or I sleep much more than before).**

- Almost Always
- Often
- Sometimes
- Never

**9) My eating patterns have changed (I have lost my appetite, or I eat more food than usual).**

- Almost Always
- Often
- Sometimes
- Never

**10) I am more irritable and short-tempered with others.**

- Almost Always
- Often
- Sometimes
- Never

**11) I am having trouble concentrating, staying focused, or remembering things.**

- Almost Always
- Often
- Sometimes
- Never

**12) I have lost interest in activities that used to give me pleasure.**

- Almost Always
- Often
- Sometimes
- Never

**13) I feel tired or exhausted much of the time.**

- Almost Always
- Often
- Sometimes
- Never

**14) I no longer spend time with friends. I have become rather isolated.**

- Almost Always
- Often
- Sometimes
- Never

**5) I feel helpless or hopeless.**

Almost Always

Often

Sometimes

Never

**What health problems am I at risk for?**

Studies show that caregivers have an increased risk for the following health problems:

- Alcohol, tobacco, and drug abuse
- Anxiety disorders
- Cancer
- Diabetes
- Heart disease, such as high blood pressure, high cholesterol, and heart attack
- Heartburn
- Infection
- Obesity
- Pain, such as muscle or joint pain and headaches
- Stress and depression

**As a caregiver, what can I do to take care of my health?**

The following are some things you can do to make sure you stay as healthy as possible during your loved one's illness:

**Make wellness a priority.** You may feel like you have to "do it all," regardless of the toll it takes on you. However, you can't take care of others if you don't take care of yourself. Take time out of your day to:

- **Eat a balanced diet.** This may be easier than you think because you may be sharing meals with your loved one, who will also need to eat balanced, healthy meals.
- **Get plenty of rest.** If you're short on sleep, take naps when your loved one does. If you can't sleep because your loved one wanders or is restless at night (this is common in people who have dementia), read "Caring for a Relative Who Has Dementia" for tips on dealing with this problem and other behavior problems.
- **Exercise.** Thirty to 60 minutes of exercise 4 to 6 times a week can give you more energy, reduce stress, and improve your mood. If your loved one is up for it, you can walk or find another type of exercise to do together.
- **Manage stress.** Your emotional health can impact your physical health. For tips on how to manage stress, read "Caregiver Stress."
- **Avoid alcohol, tobacco, and other drugs.** It may seem that these substances help you feel better for a short time, but they can affect your sleep and cause health problems if you use them regularly. If you are having trouble limiting how much you drink or quitting smoking, talk to your family doctor.

## Addendum L

**Seek treatment.** If you think you might have a physical or emotional problem, be sure to see your family doctor as soon as possible.. Your health and well-being are important.

**Visit your doctor for regular check-ups.** Even if you don't think you're sick, it's still important to see your doctor for regular check-ups. Your doctor can help you stay healthy by providing preventive services. Preventive services include health tests and screenings, vaccinations, and health advice appropriate for your age, sex, and medical and family history. These services help prevent disease and will help catch any medical conditions you do have early.

**Take a break from caregiving.** Accept that there is a limit to what you can do as a caregiver. Recognize when you feel overwhelmed or are physically unable to complete a task, and ask for help in caring for your loved one. Plan for times when you will need help by making a list of people who are willing to lend a hand. This list might include family members, friends, and temporary care workers. On your list, include phone numbers, the times people are available, and the tasks they feel most comfortable doing. Keep a copy of the list with you at all times in case you're away from home when you need to ask someone for help.

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Resilience Tree



## Resilience: A Helpful Tool for Caregivers

When life takes a turn you weren't expecting and you find yourself in a place you'd rather not be, do you fall apart or face the situation with confidence and optimism? A resilient person remains strong even in the midst of unpleasant situations.

Caring for a spouse or aging parent can lead you down a road with hard decisions, unpleasant tasks, unplanned life changes and increased stress. It is easy to become overwhelmed and feel helpless and hopeless. A resilient person will look at difficulty as a challenge, not a roadblock. They continue to feel in control of their lives even in the face of adversity. How? There are specific skills that can be learned to help you become more resilient and increase your ability to cope during hard times. Try these steps to becoming a resilient caregiver.

**1.) Solve the right problems.** Instead of mulling over things you are powerless to change, focus on what you can do. There is more than one way to solve a problem. If your first solution isn't working don't give up, just try something else.

**2.) Find meaningful activities.** As a caregiver, much of your day is filled with doing things for someone else. It is easy to lose your own individuality in the hubbub of what needs to get done. It is vital to carve out time to do something you love; something that gives you energy and recharges your battery.

**3.) Get connected.** Resilient people tend to be connected to others and reach out for help when needed. Asking for help is not a sign of weakness but a sign of wisdom and strength. Attending a support group can link you to community resources and connect you with others who are in a similar situation. This in turn will ease your stress and help you feel more positive and hopeful about your situation.

**4.) Remain hopeful.** You can't change what has happened, but you can look positively toward the future. Set goals to focus on—both long-term and everyday goals. Find a success in each day to keep you feeling positive and capable. Expect good results.

**5.) Learn from experience.** Reflect back on how you faced hardships in the past. Steer clear of tactics that didn't work and build on the strategies that were successful. When you do make a mistake—like losing your temper—don't dwell on it. Figure out what led to the error—like a lack of sleep—and fix it. Resilient people tend to find practical and correctable reasons for mistakes rather than focus the blame inward to themselves as a “bad” person.

**6.) Accept and anticipate change.** Learning to expect change helps you to remain more positive when it does inevitably happen. You can learn to be flexible and adapt to changes more easily and not view them with anxiety and uncertainty.

**7.) Take pride in your accomplishments.** When you find success, whether big or small, give yourself credit. Acknowledging that an achievement was the result of your hard work and effort rather than just good luck helps you feel capable to deal with the hardships and setbacks that come your way.

Caregiving can be full of challenges and difficulties. Being a resilient caregiver will help you adapt to the tough times and not only survive these challenges, but become a stronger and more confident person in doing so.

## **Ten Warning Signs of Caregiver Stress**

**1. Excessive anxiety and tension**

Finding yourself constantly worried about what the next day may bring, or unable to relax at the end of a long day of caregiving is a sure sign that you have taken on more than you can manage.

**2. Debilitating depression**

Feeling down about your loved one's condition is normal, but an inability to pull yourself out of a low is not, and may be a sign that you need to seek professional help for your state of mind.

**3. Persistent anger or guilt**

Caregiving will try your patience at times, and cause you to feel angry at the disease, your loved one, and even at yourself – which can lead you to experience feelings of guilt. If you find these emotions becoming more difficult to manage, it may be a result of accumulating fatigue and stress.

**4. Overreactions and emotional outbursts**

If you are beginning to cry at minor upsets, or grow irritable at the slightest provocation, you are likely less capable of managing your emotions due to stress.

**5. A general feeling of exhaustion**

When you notice that you barely have enough energy to fulfill your daily duties, it is time to take a step back and figure out ways to recharge your battery.

**6. Difficulty concentrating**

Finding yourself less focused and motivated in your daily life is a sure sign that you need to take a meaningful, refreshing break.

**7. Increasing isolation**

Losing your desire to stay in touch with friends or take part in activities you used to enjoy could be a direct result of the growing stress of your caregiving role.

**8. Trouble sleeping**

Not only is sleeplessness a sign that your stress levels are rising, it also contributes to your stress.

**9. Increased health problems**

If you are falling ill more frequently, developing persistent health conditions, and beginning to use healthcare services more often, it is time to consider reducing your stress levels at once.

**10. Excessive use of medications, drugs or alcohol**

Turning to the occasional sleep medication or enjoying a glass of wine is one way to deal with stress, but overindulging on a regular basis is a dangerous way to cope and can be another sign of mounting stress.

If you notice any of these signs, talk to your doctor, talk to your family members, talk to someone! You may feel that there is no solution and that you alone are carrying this burden. But there is support out there and there are ways to manage your stress levels and make more time for yourself.

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