Caregiver Breakout & Networking: Support and Self Care

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- I have no stocks, patent rights or employment with any company
- I have consulting/advisory board agreements with: none
- I have pre-clinical laboratory and/or clinical trial support from the following companies: none
Are you...

Taking care of a loved one

Have you...

Being taken care of by a loved one

Ever provided care for someone else (a parent, child, friend, spouse)
Congratulations…

…on taking the next hour to focus on

YOU
The *Unmet* Needs of Caregivers

- Caregivers have more *unmet* care needs than patients.
- Caregivers needs are considered *secondary* or *overlooked*.
- We need to *better understand* the needs of caregivers of people with brain tumors.
A day in the life…

• Personal care
• Mobility
• Transportation
• Communication with supports
• Housework and meal preparation
• Management and coordination of medical care
• Administration of medication and therapies
• Monitoring and managing of side effects
• Emotional support
• Managing finances
• Care for other dependents
• Maintain job or other responsibilities
• Self-care

“I don’t go out with my friends by myself as much as I used to because I don’t want to leave him here by himself.”
Depression symptoms

Forst et al., 2017
Anxiety symptoms

Forst et al., 2017
When we are stressed

• More susceptible to colds
• More irritable
• More difficulty sleeping
Three Coping Strategies

1. Relaxation
2. Coping by Controllability
3. Intention for Self-care
1. Relaxation Exercises
Stress Response

Fight or Flight Response

- Adrenaline
- Cortisol
- Sick
- Inflammation
- Sleep issues
- Stress on body
Relaxation Response

- Adrenaline
- Cortisol
- Sick
- Inflammation
- Sleep issues
- Stress on body
Goal:

Activate Relaxation Response → Dampen Stress Response
Progressive Muscle Relaxation (PMR)

<table>
<thead>
<tr>
<th>Hands and arms</th>
<th>Face and neck</th>
<th>Chest, shoulders, back</th>
<th>Thighs, calves, feet</th>
</tr>
</thead>
<tbody>
<tr>
<td>Hold arms at a 45-degree angle and make fists.</td>
<td>Raise eyebrows, squint eyes, wrinkle nose, bit down lightly, pull back corners of mouth, and pull head slightly down to chin.</td>
<td>Take a deep breath, hold it in, pull back the shoulders and puff out chest. Careful of back issues.</td>
<td>Lift your feet off of the floor, flex slightly, and turn toes inward.</td>
</tr>
</tbody>
</table>
Progressive Muscle Relaxation (PMR)
2. Coping through Controllability
Two Ways to Cope

What action can I take to resolve the situation?

Action-oriented Coping

If I can’t resolve the situation, what can I do to manage the stress/discomfort?

Emotion-oriented Coping
## Identify controllability: Snowstorm

<table>
<thead>
<tr>
<th>Controllable</th>
<th>Uncontrollable</th>
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<tbody>
<tr>
<td>Stock up on supplies (food, water, batteries, shovel)</td>
<td>The fact that a snowstorm is coming and how much snow there will be</td>
</tr>
<tr>
<td>Get a hotel room or stay with a friend closer to work</td>
<td>What areas will get hit the hardest</td>
</tr>
<tr>
<td>Leave early from work to avoid dangerous conditions</td>
<td>Whether there will be power outages</td>
</tr>
<tr>
<td>Move your car off the street to avoid towing or snow plow damage</td>
<td>Whether there will be road closures and delays in transportation</td>
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Identify controllability: Brain Tumor

<table>
<thead>
<tr>
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### Controllable

### Action-oriented coping

- What action can I take to resolve the situation?
  - Make a decision
  - Resolve a conflict
  - Seek information or advice
  - Set a goal
  - Engage in problem-solving
  - Request help

### Emotion-oriented coping

- If I can’t resolve the situation, what can I do to manage the stress/discomfort?
  - Engage in enjoyable activities
  - Relaxation, deep breathing, or massage
  - Acceptance and self-soothing
  - Exercise
  - Listen to or play music
  - Take a walk, bike ride, or other exercise
  - Talk to a friend or relative
  - Write in a journal
  - Change how I think about it
3. Intention for Self-Care

(break up into small groups)
Intention for Self-Care: 6 Steps

1. What is something I used to like to do?
2. Can I incorporate it back into my life?
3. Do I need to do it differently? Be creative
4. What might get in the way?
5. How will I overcome that obstacle?
6. Make a plan
**Example 1:**

1. What is something I used to like to do?
   - Workout at the gym

2. Can I incorporate it back into my life?
   - Maybe, but not at the gym

3. If not, can I do it differently? Be creative
   - Take a walk or jog around the neighborhood

4. What might get in the way?
   - Weather, can’t leave my loved one

5. How will I overcome that obstacle?
   - Have a backup exercise video at home or on YouTube

6. Make a plan
   - This week, Tuesday, 30 minute walk in the morning, if raining, YouTube exercise videos and choose one in advance
### Example 2:

<table>
<thead>
<tr>
<th>Step</th>
<th>Question</th>
<th>Activity</th>
</tr>
</thead>
<tbody>
<tr>
<td>1</td>
<td>What is something I used to like to do?</td>
<td>Travel to new places</td>
</tr>
<tr>
<td>2</td>
<td>Can I incorporate it back into my life?</td>
<td>No, we cannot feasibly travel right now</td>
</tr>
<tr>
<td>3</td>
<td>If not, can I do it differently? Be creative</td>
<td>Watch a travel show on a country/city and order that country’s cuisine for dinner while we watch</td>
</tr>
<tr>
<td>4</td>
<td>What might get in the way?</td>
<td>Not enough time</td>
</tr>
<tr>
<td>5</td>
<td>How will I overcome that obstacle?</td>
<td>Block out one night every other week or once a month</td>
</tr>
<tr>
<td>6</td>
<td>Make a plan</td>
<td>This week, Wednesday night, mother will watch kids, we will choose a show on Greece and eat food from a Greek restaurant while we watch</td>
</tr>
</tbody>
</table>
Complete and share with small group

1. What is something I used to like to do?
2. Can I incorporate it back into my life?
3. Do I need to do it differently? Be creative
4. What might get in the way?
5. How will I overcome that obstacle?
6. Make a plan

- Take 5 minutes to complete on your own or with your loved one
- Share with your group
- Listen and give feedback to others, help brainstorm
- Set an intention
- Check-in with that person
Share your intention:

1. What is something I used to like to do?
2. Can I incorporate it back into my life?
3. If not, can I do it differently? Be creative
4. What might get in the way?
5. How will I overcome that obstacle?
6. Make a plan
Following through…

Set an intention to practice the self-care you identified

Check-in with a group member next week
Summary

1. Relaxation
2. Coping by Controllability
3. Intention for Self-care
Thank you!
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