Living Your Best Self...as a Caregiver

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01. I have no stocks, patent rights or employment with any company

02. I have no consulting/advisory board agreements

03. I have funding from the following sponsors:
   - National Cancer Institute
   - American Society for Clinical Oncology
   - Conquer Cancer Foundation
ARE YOU... HAVE YOU...

Taking care of a loved one

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

Being taken care of by a loved one
Congratulations

…on taking the next hour to focus on

YOU
Caregivers have more unmet care needs than patients.

Caregiver’s 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 departments
Maintain job or other responsibilities

Self-care?????

CAREGIVER

“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

<table>
<thead>
<tr>
<th></th>
<th>Patients</th>
<th>Caregivers</th>
</tr>
</thead>
<tbody>
<tr>
<td>Baseline</td>
<td>22.4%</td>
<td>28.3%</td>
</tr>
<tr>
<td>3-Month</td>
<td>18.8%</td>
<td>21.6%</td>
</tr>
<tr>
<td>6-Month</td>
<td>21.6%</td>
<td>29.3%</td>
</tr>
<tr>
<td>9-Month</td>
<td>31.6%</td>
<td>31.6%</td>
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</table>

% respondents with score >7
ANXIETY SYMPTOMS

Forst et al., 2017
THREE COPING STRATEGIES

1. Enhancing Communication
2. Intention for Self-Care
3. Building Relaxation Skills
THREE COPING STRATEGIES

1. Enhancing Communication
SHARING FEARS AND WORRIES

01. If the situation were reversed and someone else was caring for you, would you want him/her to keep their worries from you or share them with you?

02. If a friend were in your situation, what advice would you give them?

03. What advice would a good friend give to you?

04. What is the worst that can happen if you shared some of your fears with the person you are caring for?

It is common for people to want to “protect” each other from their fears, worries, or sadness during this time. Ask yourself these questions:
COMMUNICATION: THE THREE Fs

**STATEMENT OF FACT**
When I see that you are running late and haven’t called.

**STATEMENT OF FEELING**
I feel nervous and worried.

**STATEMENT OF FAIR REQUEST**
I would like if you would call or text next time you are running late so that I know everything is okay and when to expect you home.
ENHANCING SOCIAL SUPPORT

How to ask for or optimize the support you need:

01 ASSESS
Assess the situation

02 IDENTIFY
Identify the type of support you need

03 IDENTIFY
Identify who might be best equipped to provide you with that type of support

04 NOTICE
Notice any barriers associated with asking for and receiving support

• Am I willing to ask for help?
• Am I willing to receive help?
• Do I think that asking for help makes me seem weak?
• Do I believe that I should be able to do it all by myself?
• Do I think that I am burdening others by asking for their help?

05 CHALLENGE
Challenge yourself as to whether your beliefs about asking for and receiving support are accurate.

For instance, is receiving support really a sign of weakness? If someone asked you for support, would you label him/her as weak? What would you tell a friend to do?
THREE COPING STRATEGIES

2

Intention for Self-Care
INTENTION FOR SELF-CARE: 6 STEPS

STEP 1: What is something I used to like to do?

STEP 2: Can I incorporate it back into my life?

STEP 3: Do I need to do it differently? Be creative

STEP 4: What might get in the way?

STEP 5: How will I overcome that obstacle?

STEP 6: Make a plan
## INTENTION FOR SELF-CARE: EXAMPLE 1

<table>
<thead>
<tr>
<th>Step</th>
<th>Action</th>
</tr>
</thead>
<tbody>
<tr>
<td>1. What is something I used to like to do?</td>
<td>Workout at the gym</td>
</tr>
<tr>
<td>2. Can I incorporate it back into my life?</td>
<td>Maybe, but not at the gym</td>
</tr>
<tr>
<td>3. If not, can I do it differently? Be creative</td>
<td>Take a walk or jog around the neighborhood</td>
</tr>
<tr>
<td>4. What might get in the way?</td>
<td>Weather, can’t leave my loved one</td>
</tr>
<tr>
<td>5. How will I overcome that obstacle?</td>
<td>Have a backup exercise video at home or on YouTube</td>
</tr>
<tr>
<td>6. Make a plan</td>
<td>This week, Tuesday, 30-minute walk in the morning, if raining, YouTube exercise videos and choose one in advance</td>
</tr>
</tbody>
</table>
## INTENTION FOR SELF-CARE: EXAMPLE 2

<table>
<thead>
<tr>
<th>Step</th>
<th>Question</th>
<th>Option 1</th>
<th>Option 2</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>
<td></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>
<td></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>
<td></td>
</tr>
<tr>
<td>4.</td>
<td>What might get in the way?</td>
<td>Not enough time</td>
<td></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>
<td></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>
<td></td>
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</table>
THREE COPING STRATEGIES

3

Build Relaxation Skills
THE FIGHT OR FLIGHT RESPONSE

↑ Adrenaline
↑ Cortisol
↑ Sick

↑ Inflammation
↑ Sleep issues
↑ Stress on body
THE RELAXATION RESPONSE

↓ Adrenaline
↓ Cortisol
↓ Sick

↓ Inflammation
↓ Sleep issues
↓ Stress on body
GOAL OF BUILDING RELAXATION SKILLS

Activate Relaxation Response

Dampen Stress Response
## PROGRESSIVE MUSCLE RELAXATION (PMR)

<table>
<thead>
<tr>
<th>01</th>
<th>02</th>
<th>03</th>
<th>04</th>
</tr>
</thead>
<tbody>
<tr>
<td>HANDS AND ARMS</td>
<td>FACE AND NECK</td>
<td>CHEST, SHOULDERS, BACK</td>
<td>THIGHS, CALVES, FEET</td>
</tr>
</tbody>
</table>

**01**

- Hold arms at a 45-degree angle and make fists.

**02**

- Raise eyebrows, squint eyes, wrinkle nose, bite down lightly, pull back corners of mouth, and pull head slightly down to chin.

**03**

- Take a deep breath, hold it in, pull back the shoulders and puff out chest. Careful of back issues.

**04**

- Lift your feet off of the floor, flex slightly, and turn toes inward.
Progressive Muscle Relaxation (PMR)
ADDITIONAL RESOURCES

Caregiver Resource Center
Caregiver Handbook

Connections – ABTA’s online brain tumor support community for patients, survivors, and caregivers
CommYOUUnity Connect – ABTA’s peer mentoring program for patients, survivors, and caregivers

www.cancercare.org (caregiver groups online and over the phone)
MGH Program for parents: http://www.mghpact.org/forparents/parents

https://livehelp.cancer.gov/app/chat/chat_launch (NCI live free information)
Cancer Support Community: https://www.cancersupportcommunity.org/MylifeLineMemberStories

Mobile Apps:
- Insight Timer
- Calm
- Headspace
- Stop Breathe and Think

Full Catastrophe Living by Jon Kabat-Zinn
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THANK YOU

Any questions?