SESSION 1: INTRODUCTION AND MANAGING STRESS

Getting to Know You

Please share a bit about yourself and how you have been coping since the person you are caring for was diagnosed.

When we are faced with a situation that causes worry, nervousness, or uncertainty, two reactions are common:

• One way is to seek reassurance by searching for information, questioning, guidance, and support. This can be helpful in small doses but can become unhelpful if done too much, or we are not satisfied with the answers and continue seeking reassurance (e.g., hours of scouring the internet).

• Another reaction is avoiding people, places, or things that remind us about our situation as to avoid getting upset. In the form of temporary distraction, this can be helpful, but can be unhelpful if it leads to denial or procrastination about important decisions or discussions.

Do you notice yourself in either of these patterns? Both seeking reassurance and avoidance are attempts to feel more in control of a situation, but to the extreme, both are more harmful than helpful. Throughout this program, we will help you find a middle ground amid all the uncertainty.

AGENDA

In today’s session, we will:

1 Get to know each other and identify your biggest worries and concerns

2 Learn simple and helpful ways to manage common concerns including guilt, self-doubt, and stress

3 Understand how our bodies respond to stress

4 Learn to relax by breathing with our diaphragm
## Identifying Common Concerns

Caring for someone with cancer can lead to concerns about family, relationships, work, and home lives. It is common to experience emotions such as sadness, nervousness, or irritability during this time.

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Place a number from 0-10 next to each concern below.

*0 = I am not concerned about this; 10 = I am extremely concerned*

<table>
<thead>
<tr>
<th>Concern</th>
<th>Score</th>
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<tbody>
<tr>
<td>Financial responsibilities and/or communicating with insurance</td>
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<tr>
<td>Being a health care proxy/surrogate decision maker</td>
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<td>Managing medications and multiple medical appointments</td>
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<td>Taking on things that my loved one used to do (e.g., driving, cooking, bills)</td>
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<td>Whether I am doing a good job as a caregiver</td>
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<td>How to manage my own emotions (e.g., worry, sadness, anger)</td>
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<td>Knowing how to help my loved one</td>
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<td>My loved one having a recurrence or progression of cancer</td>
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<td>My physical ability to care for my loved one</td>
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<td>How my relationship with my loved one will change</td>
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<td>Resenting or feeling frustrated towards my loved one</td>
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<td>Changes in socializing with friends or family</td>
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<tr>
<td>Communication with my loved one</td>
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<td>Questions and/or uncertainties about end of life</td>
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<td>When or how much to call the health care team</td>
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<td>My loved one’s emotional well-being</td>
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<td>Managing my loved one’s physical or cognitive symptoms</td>
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<td>My loved one dying</td>
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<td>My own physical health (e.g., getting sick, not sleeping)</td>
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<tr>
<td>Chemotherapy and/or radiation</td>
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<td>Getting (or not getting) help from family and/or friends</td>
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<tr>
<td>How to manage my job and/or talk to co-workers</td>
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<tr>
<td>How to talk to my children or other family members</td>
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<tr>
<td>Envisioning life without my loved one</td>
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Have you ever found yourself thinking of things you “should,” “must,” or “ought” to do? While caring for someone else, we might try to do it all, thinking, “I ought to be able to do this myself,” or “I shouldn’t have to ask for help.” We have high expectations and are our own toughest critic. As a result, it is very common to feel guilt, shame, or worthlessness.

Guilt stems from feelings that you are not doing enough, not saying enough, or not behaving in the “right” way. Some notice feelings of guilt around being “the healthy one.” You may feel “guilty” when you take time to care for yourself, or to focus on your needs. However, it is important to remember that you need support as well.

When you notice guilt:

1. Ask yourself: do I truly believe that I am not doing a good enough job?
2. Think of what you would say to a friend if they were in your situation
3. Remind yourself that by taking time for yourself, you will be a better partner and caregiver to your loved one
4. Think of what a good friend might say to you
5. Ask yourself: Is it okay to ask for help? How can I get the help that I need?
6. Aim for flexibility in your thinking. Avoid words like “should,” “ought” and “must”
7. Remember that it is normal to feel this way
8. Try not to beat yourself up or be overly critical
Am I doing a good enough job?

Many people wonder whether they are doing a “good job” as a caregiver. Some worry that they will miss something about their loved one’s health, so they spend a lot of time checking in, asking questions, and searching for answers on the internet. While sometimes helpful, too much checking in, asking, and searching can make your stress and worry worse. In these moments, consider the following:

1. Remind yourself that you can trust the medical care team and direct your questions to them
2. Remind yourself that you are not a bother to the team, they care, and their job is to help
3. Ask yourself: am I doing the best that I can?
4. List some things that you are doing well
5. Try to limit time on the internet that may result in more questions

Strategies for managing stress and medical visits:

Caring for someone with cancer is more than a full-time job and can be stressful in addition to all your other responsibilities that, unfortunately, do not disappear. There are a few things that you can do to stay organized:

1. Take notes and keep them together in a folder or notebook
2. Summarize and compare notes with your loved one immediately after the appointment
3. Keep a running list of questions in between appointments
4. Bring another person with you to the appointment to be a listener and/or note-taker
Relaxation Training

One way to reduce suffering and stress is with relaxation.

When we respond to something stressful in our environment (e.g., a loved one’s diagnosis or even being stuck in traffic), our bodies prepare for the “fight or flight” response. This response is a biological process designed to protect us from danger and to ensure our survival, releasing hormones and chemicals (e.g., adrenaline), and increasing our heart rate to pump blood to our muscles so that we can act fast. While this response is helpful in the short-term, it can be difficult to turn this off, and you may find yourself in a constant state of stress.

Relaxation is a tool to turn off or dial down this stress response when it is no longer helpful, and to calm our body and mind when we are in a situation over which we have little control (e.g., a loved one needing treatment for cancer, or traffic).

When you teach your body to relax, you can lessen your stress response by lowering your heart rate and blood pressure and decreasing the release of cortisol, a stress hormone. The more you practice the active process of relaxing, the better you will become at calming your body in a moment of stress or worry.
Illustrating the connection between thoughts, feelings, and physical sensations

Let’s take a moment to understand the strong relationship between our thoughts, feelings, and physical sensations in your body.

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Sit back, get comfortable in your chair, and close your eyes. Imagine yourself in a place you like or would like to go. This can be somewhere you have been or somewhere you have been longing to go. Notice your surroundings and certain details about this place to make it as real as possible in your mind’s eye. How does it feel to be here? Notice any emotions that arise, perhaps a feeling of peace, calm, or even happiness. Also notice any physical changes in your body. Perhaps your muscles start to loosen, relax, or unwind. Perhaps you notice your breathing slowing. Keep this picture in your head for another few moments as you imagine really being in this place that is special for you.

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Now, we are going to try something different. For a moment, imagine yourself anywhere else, but with someone you know whom you have difficulty with. This can be a person you are upset with right now, or someone you have had a difficult relationship with in the past. Think of some of the challenges you have had with this person and how this makes you feeling emotionally. Do you notice yourself feeling frustrated, hurt, or upset?
What physical sensations do you notice in your body? Do your muscles tense, does your heart start beating faster, or do you get a knot in your stomach? Now, allow yourself to return to a neutral place and come back from these images and back to the room. Take a deep breath and open your eyes.

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What did you notice in your emotions and body as you imagined being in the special place? What did you notice in your emotions and body as you imagined yourself with someone you have had difficulty with? Although you are not actually in this special place, we respond to the thought of being there as if we were actually there, illustrating the incredibly strong connection between our thoughts (being in this special place) and physical sensations (relaxation, muscle release, heart rate slowing, breathing slowing). Similarly, although you were not actually with this difficult person, the thought of being with them is stressful and illustrates the strong connection between our thoughts (about this difficult person) and physical sensations (muscle tension, knot in stomach, heart racing).

Stress works in the same way. We perceive something to be stressful (thought), and our body responds by releasing stress hormones (physical sensation). Relaxation can slow the release of stress hormones.
Relaxation Exercise: Diaphragmatic Breathing

Also called deep breathing, or belly breathing, breathing with the diaphragm is helpful way to create a relaxed state. Over time, and in stressful situations, we tend to engage in “chest breathing,” resulting in shallow, more constricted, tense breaths. Diaphragmatic breathing allows for full oxygen exchange, slows the heartbeat, and lowers blood pressure, creating a state of relaxation.

Try these simple steps:

STEP 1: Lie on your back with your knees bent or sit in a chair with both feet on the floor.

STEP 2: Place one hand on your upper chest and the other on your belly, below your rib cage.

STEP 3: Breathe in through your nose, taking the air in deeply, and letting your belly expand.

STEP 4: Breathe out through pursed lips, tighten and contract your abdominal muscles, letting your belly fall as you breathe out completely.

STEP 5: Imagine that your belly is a balloon, and as you inhale, the balloon inflates, and as you exhale, it deflates.

STEP 6: As you practice, the hand on your belly rises and falls with each inhalation and exhalation, while the hand on your chest remains still.

Practice for 5 to 10 minutes a day.
Take a moment to close your eyes, with both feet on the floor. Bring your awareness to your breath as you inhale...and exhale.

Notice breathing in...and notice breathing out. Briefly scan your body...are you holding tension in any muscles, your neck, shoulders, or jaw?

Try to relax those muscles, breathing in...and breathing out.

Thoughts might come in to your awareness, and that is okay, just let those thoughts be; you don’t have to be anywhere or do anything to change them. Just allow yourself to be...right here...right now.

Focusing on your breath, inhale...and exhale.

As you come to the end of this exercise, remember that you can return to this feeling at any time or place throughout your day.

When you are ready, wiggle your toes and fingers, and slowly open your eyes, feeling refreshed, relaxed, and alert.
1. Choose one strategy from Session 1 to manage feelings of guilt, worries about being a good caregiver, or managing stress and appointments. We will talk about how this went for you at our next session.

2. Find a quiet, private space and practice diaphragmatic (belly) breathing for 5-10 minutes once a day.
Notes

You can use this “Notes” section to jot down thoughts about the session or the practice exercise. You may also use this space to write down questions to ask the healthcare team, reminders to yourself, or questions for your next session with us.

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