Balance in the Eye of the Storm: Self-Care when Caring for a Loved One with Mental Health Concerns Transcript

The topic for this presentation is, “Balance in the Eye of the Storm: Self-Care When Caring for a Loved One with Mental Health Concerns.” I want to start by giving you a bit of an overview that describes how we will focus our time.

Today our focus is related to the caregiver burden when caring for a loved one with mental health issues. Caregiver burden is a real and valid concern. With all of the uncertainty and potential stormy disruptions that arise when caring for someone who is struggling with mental health issues, you surely are in need of all the tools available to help you care for yourself when trying to respond to the needs of your loved one.

Our goal is to help you find and maintain your balance, as well as manage your own self-care, even if you are living in the eye of the storm.

We will begin by identifying how you can notice that you are out of balance by recognizing the feelings, thoughts, physical sensations, and behaviors that may be signals that you are under stress. We will then talk about some of the tools that you can adapt to help keep yourself balanced. Finally, we will discuss some of the potential supports that you may use to help you care for yourself.

Learning that your loved one has a mental health diagnosis often brings up a wide range of negative emotions and feelings for both the person with the diagnosis and the caregiver. Living in a home with the challenging effects of a person’s mental illness can result in problems such as marital adjustment, communication difficulties, changes in household roles and financial problems. Perhaps problems include feelings of mistrust, shame, anger, fear, isolation, and embarrassment. The longer these problems continue without being addressed, the bigger the burden that you bear and the larger the toll on your own wellbeing.

There are challenging differences when caring for someone with a mental illness versus a physical illness. Mental illness is not visible to the naked eye and the symptoms often increase and decrease unexpectedly, leaving the caregiver “walking on eggshells” and never knowing what to expect. This may lead caregivers to more easily get caught up in reacting and responding to the turmoil their loved one is experiencing and results in caregivers feeling their own turmoil.
Have you been caught up in the storm of your loved one’s illness? How do you notice it? What steps do you take in order to regain your sense of balance? Can you remember the last time you felt this way?

Are there physical things that you notice when you begin to get caught up in the upset around you? Do you feel your heart pounding, your stomach muscles tightening, your fists clenching, or were you clamping your teeth together so you wouldn’t say something you might regret?

Are there emotional reactions that you notice in yourself when you are becoming off balance? Do you become more quiet or blue? Do you find yourself more worried or anxious? Are you short tempered, irritable or angry?

I’ll give you a few minutes to reflect on the last time you became upset and reacted to your loved one’s illness. What did it feel like when life got stormy? What emotions, feelings and behaviors did you experience in that moment?

Thank you for reflecting on these questions. The reason why this is important is because when you are able to recognize these feelings and reactions, you are identifying the signals that are telling you, “Whoa. Slow down. Things are getting out of control.”

When you know what to look for, you can then learn how to adjust your reactions and your responses. Your attention to your own feelings, thoughts, behaviors and physical responses is an important first step in responding to an emotional situation in a way that isn’t reactive, but is really a purposeful response in which you are in charge. Your awareness of yourself, what is happening around you and how you are responding can help you to maintain your own balance and stability.

Paying attention, either in the moment or giving some thought or reflection after the fact, can help you to get some perspective when dealing with stresses. If you review stressful situations and break down the chain of events to specific components, you can better sort out not only what is upsetting you and what your reactions are, but also help you to sort out how you can manage them in the most productive way possible.

What is it that you think, feel and do that alerts you that you are starting to get off balance? What “red flags” can you look for in your life that signal “danger ahead?”
These reactions are usually placed into four categories: feelings, thoughts, physical responses and behaviors.

Let’s take a look at what you may notice in each of these categories, so you are more aware of when you are getting a warning sign or symptom in which you need to pay attention.

Let’s begin by looking at the feelings that may be a red flag. Your feelings may be indicated by some of the following: Are you noticing that you are angry, short tempered, or impatient? Maybe you are feeling sad or blue. Are you confused or overwhelmed? Maybe you notice that you are so agitated you can’t relax. You might be aware of feeling hurt and unappreciated. You could be deeply lonely. You may even notice not feeling anything at all, feeling numb, when you know you shouldn’t be because you have shut off all your feelings from the strain you’ve been under.

Now, what about your thoughts? Do you notice any of these thoughts when you are under stress? Memory problems, confusion, and the inability to concentrate may occur when you are doing too much and are being pulled in many directions at once. Have you experienced any of these problems? You may notice that constant worried thoughts seem to have become a habit. Do you find yourself worrying about everything and then trying to control the people or your environment so that you can attempt to get some order? Maybe you are finding you are having trouble making decisions, that even trying to decide what to fix for dinner seems impossible. Pessimistic or negative thoughts can arise when you don’t know what to expect. Does this sound familiar? Do your thoughts go down this path?

Next, your physical responses can be a powerful warning sign and your body’s way of communicating with you through its physical responses? Are you experiencing physical signs such as: nausea, or general GI problems, maybe your blood pressure is elevated or you notice your heart pounding or tension in your chest or back. Some people have more frequent headaches, or are more prone to getting sick. You might notice increased tension in your muscles, shoulders, or jaw from clenching your teeth. When your body is trying to get your attention in these ways, most likely you have ignored yourself for a time.

Finally, behaviors, or your actions, can often indicate that you are not at your best. Are you eating too much or too little, and sleeping too much or too little? Sometimes eating too much or sleeping too much is a sign you may be trying to soothe
yourself when you are upset. Do you find yourself withdrawing, isolating yourself from others?

Sometimes people use alcohol, cigarettes or other drugs to relax. It is very easy to increase your amount of use without being fully aware you are doing so, until you are in trouble. Careless or reckless behaviors that affect caregivers can include speeding or inattentive driving, excessive spending, gambling and giving into temptations that bring quick, temporary happiness, but often with a cost to you and yours. Each of these behaviors can be a red flag or warning sign that you have lost your equilibrium or are struggling with the stress you are under. If you pay attention to them, your behaviors can inform you that you need to take action.

When you are aware of the feelings, thoughts, physical reactions, or behaviors that are warning you are off balance, you can then take some time to explore and learn about what happened that triggered the reaction.

So, if you are getting a warning sign that you are running into difficulty, you can ask yourself, “What is the triggering event here?” Sometimes it is necessary to sit back and think, “What just happened?” It can help if you can find a way to slow down, to be a curious observer, and look at the situation as a detective would, examining the situation from all sides. Don’t worry if you can’t do this in the moment. It’s tough to get perspective in the moment when you are in the midst of all your feelings and reactions. After you calm down though, try to take time to understand what happened. If you can take the time to identify your trigger you will be better prepared the next time.

Recognizing your reactions is the first and most powerful step in taking care of yourself. It is a sign of strength to know where you are vulnerable. Consciously or unconsciously, you may purposefully try not to notice the signs, symptoms, behaviors, or physical reactions within yourself. You may not want to sit with how you feel. You may not want to look at your reactions. It may seem too painful, so you just deny them and tuck them away. After a while though, you will see that this will simply build into a bigger warning sign. You pay the price of not attending to your feelings. One way or another, they will find a way to get your attention.

Accepting your feelings is a critical piece in getting relief. These are your feelings and emotions. It doesn’t help to make excuses for them, to get angry at them, or to pretend they are not there. Accepting them as they are will in fact empower you. Once you accept them as yours, once you stop resisting them, not only will you feel relief, but you can use this self-knowledge to develop your action plan.
Another important component of your strategy to find your way out of the storm is through education. Building on your knowledge by reading reliable information regarding your loved one’s diagnosis and learning more about what triggers his or her signs, symptoms and behaviors, can help you better understand what is going on with him or her, make you less likely to take it personally, and you will find you are more able to plan how to manage or cope with problems.

The internet, the medical providers you work with, the National Alliance for Mental Illness, the Alzheimer’s Association or any number of reputable agencies may be helpful. The list of potential organizations that can help is vast. Make use of the knowledge and support these people and organizations can provide. Education and support is a vital tool to secure what you need to stay stable.

At this point, we have spent some time learning about how to get out of reaction mode and move to being proactive towards recovering our balance. Now we will look at potential action plans that, along with the skills we have already talked about, will also help you to get back in balance again.

In developing your plan, there is one very important fact to remember. This is a plan for you, to help yourself move out of the storm. It is not a plan to fix the storm or the Veteran. Both of these fixes are impossible, because they are not within your control!

Despite this fact, every one of us has probably tried to change another person’s behavior by talking with them reasonably, or yelling, or trying to manipulate the environment so there is less stress and fewer problems, but this is wasted energy. It does not work for one simple reason; the only person that you can change in this whole wide world is you. This is a hard lesson for every one of us to learn. So much energy is wasted in trying to change another person, and that energy could be better used to focus on your own options and strategies to take care of you.

Now, this doesn’t mean that because you can’t change the person, you have to sit back and quietly accept everything. It does mean that ultimately, the only person that you can have any choice about changing is you. You can let your loved one know honestly how you are feeling, or what your limits are, or what you are hoping for, but beyond that, you are the only one who can make changes and live with your choices.

Sometimes when you are upset, you may struggle with coming up with a plan for yourself. When you are upset it is easier to get stuck, to not see any options, and that
makes the upset seem even worse. You see no way out. If you can let yourself brainstorm or imagine, without any judgments, without cutting out ideas before you let them blossom, a plan to take care of you, you can in fact find many options that may provide some help.

Let's brainstorm some solutions that may help you cope with the unique challenges of your loved one's mental health concerns.

We will begin with Post-Traumatic Stress Disorder, otherwise known as PTSD. Those who suffer from PTSD have experienced a devastating trauma and deserve our support, understanding and compassion. One of the ways those with PTSD may protect themselves from the distress of their traumatic memories is to cut themselves off from their own feelings and from their emotional connections with their loved ones. This may result in leaving their loved ones feeling alone as well. So, while you want to provide comfort and compassion, you also want to let them know that we want and need their connection and emotional presence. If you are feeling cut off from your loved one, consider ways that you may contribute to soothing, comforting, and learning about their struggle that will in turn help you feel like their partner, and bring back the closeness that may be missing.

Has the agitation and anxiety that accompanies PTSD begun to feel as though you are tiptoeing around a time bomb? Are you expending energy trying to keep a clear path so there are no upsets, only to find yourself worn-out and fed up from the explosions and anger? While there may be emotional outbursts, it is important to set clear limits that you will care for your own safety. It is also reasonable to get together during calm times to try to understand what happened, what may have triggered the episode, and for your loved one to hear how it is for you during the storm.

Perhaps there are nightmares that leave you and the Veteran without sleep and feeling frightened. Can you discuss plans that may help you get rest, as well as help soothe both of you from the upset?

Next, let's consider options for self-care if your loved one has Alzheimer's disease, Dementia or other neurocognitive disorders. These illnesses have a progressive and irreversible nature that can cause Caregivers to feel unappreciated, frustrated and exhausted as they manage personal care needs, answer the individual's endless repetition of the same questions, or struggle with disruptive behaviors and sleep schedules.
Because of the unique demands of these illnesses, oftentimes caregivers are left feeling very isolated in caring for their loved one, and this isolation along with the tremendous strain of care, can be a real challenge to your health and balance.

Seeking out resources and supports, and identifying for yourself who may help and how, may break the isolation. There are many ways to stay connected to others and to benefit from their support. Making a phone call or writing an old friend, seeking out support groups in your community where you can connect with others that have similar struggles are options you may pursue. Sometimes, it seems difficult, with all that you are doing, to make the effort to reach out, but even having contact with other people a little bit each week can provide a noticeable relief in your stress levels.

Trying to get regular rest from your caregiving chores can keep you from becoming irritable and short tempered. Explore how you might get breaks for yourself, whether taking an afternoon nap or looking at who might help so you can get out of the house, are a couple of options.

Having a routine can help someone with dementia feel less agitated and distressed. While you are keeping routines that provide comforting stability to your loved ones, make space in those routines for yourself. Be sure to include the rituals and hobbies you enjoy into your daily or weekly routine.

Each challenge that your role as caregiver presents can be examined to brainstorm potential options for plans. The trick is to not get stuck in the problem, but to explore ideas freely.

Next, if you are struggling with providing care for someone who has Chemical Dependency concerns or other addictions, you may frequently experience mistrust, embarrassment, anger, and may find yourself becoming overly responsible by taking on the task of trying to control or change your loved ones’ behavior, both to protect them but also to protect yourself or your family from the negative consequences of their addiction. Finding ways to cope and to recognize what you do, and do not, have control over is essential.

Again, you cannot be responsible for anyone’s behavior but your own. While you can be understanding and loving regarding your loved one’s struggle, and support their efforts to get help, you may also need to set some clear limits around not supporting their addiction by making excuses for their behavior with their employer or family members, or by financially supporting their addiction. Arguing with someone when they
are intoxicated or under the influence of drugs is a waste of energy. Communicating clearly when your loved one is sober and clear-headed is critical.

The best you can do is to be clear about what your limits are and to also be clear about the impact the addiction is having on you and your hopes for the person who is struggling.

Finally, if your loved one struggles with Depression or Bipolar Disorder, their symptoms can impact Caregivers in unique ways. The person descending into depression or climbing into a manic episode may pull family members along with them just as a tornado sucks objects into its whirling center and can leave you feeling exhausted, depleted and in a world of chaos.

So again, you will need to find ways to keep your own balance by caring for your own emotional reactions and setting boundaries to help manage the ups and downs, as well as the potential erratic behavior of your loved one.

Caregivers can struggle to recognize and manage their own mood when they are close with someone whose moods are strong. You may need to be extra aware of your own mood, maybe by getting some space, calling on a friend, or seeking another support for yourself, will help you keep your balance. Staying physically active or engaged in your own interests may also help you stay centered.

Learning about the illness and learning what to expect, can give you a great deal of information to guide your plans for caring for yourself. You may be the first one to take note of your loved one’s changing mood. Not only can this help them take better care of themselves, it also can help you keep your life more stable as well.

Again, our guidance today is general and not meant to be viewed as a treatment recommendation. Seek out your Veteran’s treatment team or your own medical provider as a source of specific direction and help when you are struggling with providing care.

One of the most critical connections that you can make in caring for yourself is the ability to be open to exploring any and all of the supports that may be available to help you stay centered and manage your own balance when caring for a loved one with mental health concerns.

Many local newspapers list support groups. Your own doctor or medical provider may know where to find help. Your local 211 or Lifeline phone number is a great
clearing house of resources and support in your community, and connecting with the National Alliance for Mental Illness chapter in your area is a great place for education and support. The important step here is to reach out, ask someone, and place a phone call or two. It can turn out to be one of the best things you’ve done for yourself.

We have covered a great deal of material. Although we cannot make a plan with all the particular strategies that you may need, we hope that we have helped you look at a guide that may help you move forward feeling clearer, more purposeful and feel a greater sense of being solid and grounded in yourself rather than feeling swept up in the storms of caring for another.

To review, the powerful first step is to be aware of when you are feeling distressed. You will want to recognize what has triggered the reaction, and then move toward accepting your feelings, learning about yourself, your reactions, and your loved ones illness. Develop a plan which includes brainstorming as many solutions as possible in a calm place and be open to developing and seeking out a network to support you. There are many web pages, call lines and agencies that are in place to assist you in caring for you while you are caring for your loved one.

Thank you for your continued commitment to the care of your Veteran loved one. We honor your efforts and encourage you to care for your own needs as well as you have been providing for others. We at the Caregiver Support Line are just one port in the storm, to help you brainstorm or to provide the support you need. We are only a phone call away.