



Caregiver Support Line Presentation - Transcript

Series: Care for the Caregiver

Topic: Standing on Solid Ground: Finding Your Path along the Challenging Road of Caregiving and Mental Illness

Hello. I am so pleased that you were able to set aside this time to listen to this presentation. We all know how difficult it can be to take the time to focus on you and your own needs, so we hope this presentation will be a worthy use of your valuable time.

The topic for this presentation is, "Standing on Solid Ground: Finding Your Path along the Challenging Road of Caregiving and Mental Illness." It has been over 50 years since President Kennedy's landmark legislation, The Community Mental Health Act, was signed into law. Despite its ambitious and far reaching initiatives to bring attention and resources to the needs of those suffering from mental illness, our nation and its people continue to suffer from the misguided beliefs and alienating stigma that mental illness evokes.

The evidence remains all around us that our culture continues to view mental illness as somehow different than any other physical illness. Unlike heart disease, diabetes, or cancer, mental illness on the whole remains an unspoken, shadowy, misunderstood flaw that must be hidden, and as a result the added burden of stigma remains.

Those suffering from mental illness and those caring for those suffering from mental illness not only struggle with the effects of the illness, but then also suffer from the equally burdensome weight of its stigma. Isolation, shame, guilt, grief, confusion, frustration, bewilderment are but a few of the potential added burdens that our Caregivers may encounter in their journey.

The struggle to bring clarity and reason to the issue of mental illness forges on. Our Caregivers along with their loved ones deserve to have a path that is clear of the stigma so that they may support their loved ones and be supported themselves towards the solid ground of recovery. It may be helpful to consider what keeps these roots of stigma alive as these are some of the very forces that may contribute to you and your loved ones isolation and suffering.

First, there has been and remains great mystery to these illnesses. We have struggled to understand the biology at work in their development and the biology that influences



the profound impact on the sufferer's thoughts, emotions and behaviors. Whenever there is a mystery it is human nature to try to explain it even if the explanation has no bearing on the facts. Throughout the ages inaccurate conclusions have been drawn that have only added to the burden that the sufferer must carry.

Another reason these illnesses have been so misunderstood and mysterious may be that many of the symptoms are difficult to understand, may seem strange, may come and go unexpectedly, and are evidenced by profound and sometimes disturbing shifts in mood and behavior. Isn't it understandable then in the light of such mystery, uncertainty, or discomfort, that one may either jump to inaccurate assumptions or result in wanting to bury the whole subject underground?

When we learn to look clearly and logically at the facts of the illness we are taking a step towards diminishing the stigma and judgmental assumptions that the mystery fuels. Learning about the symptoms of the illness, the potential triggers, the patterns or course of the illness, and the treatment options available, is a powerful tool you can invest in to help you find solid ground.

Learning about the illness can also help you more clearly distinguish between the person and the illness. Your loved one may suffer from symptoms of schizophrenia, bipolar disorder, PTSD, substance abuse, alcoholism, or Alzheimer's disease, but they are not their illness. Despite the extent the symptoms may impact their functioning or color their interactions with you, they remain first and foremost a unique and valued individual.

So, getting the facts and learning how the illness and its symptoms are occurring in your loved one can help you be less reactive, unprepared, and taken off guard when the illness is impacting you and your loved ones wellbeing. Getting the facts can help you to distinguish how you might help and help you to be clear what your loved one is responsible and capable of taking care of. Having knowledge of the particular illness can help you to tailor your approach to caring.

Maybe you are asking yourself, "Really, how is it going to make any difference to me if I learn more about the illness? I'm still going to have to deal with the symptoms," and you know, that is a fair response, but just consider the last time you tried to find your way somewhere without directions. Were you frustrated? Did you feel lost or vulnerable, get irritable, or confused? When you are coping with symptoms, moods, behaviors, that are bewildering, that shift from one day to the next, that create havoc at home, that are embarrassing to you or infuriate you or sadden you and you don't have



the knowledge or understanding to make sense of it this, it will make your distress so much worse.

There are many sources of information available that are free and able to provide you clarity not only about the illness and its symptoms but how to help you cope so that you can find your way out of the uncertainty.

The National Alliance on Mental Illness or NAMI is one very helpful resource that one can turn to get free education about the specific mental illness your loved one suffers from. Each particular mental illness has specific identifiable symptoms, a course and pattern, and potential treatment options. Having the information that you need could help you see the illness clearly as well as help you understand how to help you and your loved one cope with it.

NAMI also provides free support groups throughout the country for family and friends to share their struggles, and their solutions. This is the very kind of support and information that will shed light for your safe passage on the road ahead. Again, it is just one source of information and support to call on and as easy to connect with as picking up a phone book.

The Alzheimer's Association is another such source of information related to dementia. There are so many ways you might get the information that you may need to empower you to understand clearly what is happening to your loved one and the kinds of things that you can do to help them remain safe and stable and in turn will keep you from spiraling into the uncertainty of reactivity.

When you are burying your head in the sand or when you are uninformed, you are opening the door and stepping out onto shaky ground. If however you seek out information via the internet, books, community agencies such as NAMI, the Alzheimer's Association, the VA PTSD Information Line, Alcoholics Anonymous or Al-Anon, to name just a very few, then you are building on your own resilience and stability. So, consider learning more and then bring your attention to how this helps you remain calmer, clearer, more grounded, and more effective in your caring.

While a lack of knowledge is one of the roots of distress, there are a host of emotions that left unattended may profoundly impact your thoughts, reactions, and your health and wellbeing. Again, not looking at these emotions squarely isn't going to make them go away. Paying attention to them and learning from them however, will.



First and foremost, your emotions are a powerful source of information. Your emotions can act as a barometer of how you are doing, how stressed you may be, and as a result provide direction for what it is you may need. Your emotions can also alert you if you listen, to what your limits are and therefore provide guidance regarding how you need to care for yourself. Now, mind you, despite how important it is to be clear about your feelings in order to stay centered, recognizing squarely how you feel may not be at all easy or pleasurable. Despite it not being always easy or pleasurable attending to your emotions is a critical skill in negotiating the path forward.

Why, you might ask, does it help to face head on that I may feel ashamed, embarrassed, sad, angry, frustrated, confused, lonely, anxious, worried, or any other number of painful feelings? You might say, “It doesn’t feel good, so why shouldn’t I try to pretend they are not there?” Well pretending or ignoring takes energy, and while most feelings come and go if properly attended to, pretending and ignoring just keeps them from passing naturally. So all those feelings you are investing your energy in trying to ignore, simply creates a pile up of emotion that obstructs your view and wears at your sources of energy.

Sometimes you may act out your emotions in a self-destructive manner such as lashing out impulsively, withdrawing, or any number of compulsive activities to try to forget; like over eating or drinking or spending. If you properly face the feelings you have by noting them, sitting with them, learning from them and letting them pass naturally, your actions forward will be more solid, purposeful, and a more accurate reflection of who you are.

Let’s explore a bit some of the feelings that may emerge as you take this path as a Caregiver of a loved one with mental illness.

Feelings of shame can be a debilitating consequence of the stigma related to mental illness. Your loved one’s illness may cause them to not take care of their physical appearance. It may cause them to say or do things in public that aren’t appropriate. It may impact their interactions with others or what others think of them. It may impact household stability or financial security. All of these uncomfortable consequences can result in you taking on the burden of shame. When you are ashamed, you may inadvertently try to change or control some aspect of the illness that is out of your control in an attempt to avoid the shame. For example, you may place expectations on your loved one that are unfair or unrealistic in order to avoid how you feel. Efforts to force another person to change even if they were able to alter their behavior, is going to leave you feeling wrung out and frustrated.



Maybe shame causes you to withdraw and isolate so that you don't have to face feeling embarrassed. Again, hanging your head in shame because of the consequences of your loved one's illness is a burden, and that weight will interfere with you holding your head up and seeing clearly your path.

If you can face these feelings you can clarify, "Hey this is the illness. This behavior is not a reflection of me or my loved one's worth. It is merely the effects of the illness." Neither you nor your loved one is defined by the effects of the illness. Facing such feelings with the clarifying facts can remove the veil of shame interfering with both of you moving forward.

Anger and frustration are other feelings that may come when your loved one's illness causes chaos or interferes with your desires and plans. Maybe their illness is impacting your sleep or finances or your mood. Maybe you are frustrated with the demands of their care needs.

Anger and frustration are normal emotions that deserve your attention and care. They are certainly unpleasant feelings but it is alright to admit that you are in fact angry. Anger and frustration arise to inform you in the most basic way to take care of yourself. You get angry because you feel threatened or vulnerable somehow. Getting angry and frustrated may come when you have been expending yourself and are depleted; when you have no more energy to give. Your emotions are saying, stop, and take care of yourself.

Getting angry or frustrated isn't something to either feel guilty about or to avoid. It is there as a warning sign asking you to pay attention. Again, you want to use your feelings as a guide for purposeful action; not to react impulsively or act out in a way you may regret but to simply take notice and take thoughtful action. Just because our loved one has an illness does not mean that you must accommodate them at your expense. You have a right to set your limits and expectations.

So what is your anger or frustration asking you to look at? Is it; "Do I need to take a break from caring? Do I need to say no to someone or something? Do I need to be listened to or understood? Do I need to ask for help or support? Do I need to set clearer expectations?" Listen to that voice wisely. It is a force that will keep you solidly upright and moving forward.

Maybe you are most struggling with feelings of anxiety, fear, or worry. Not knowing how your loved one is going to behave, if they are going to be safe, if they are going to get



the help they need or take their medicine necessary to maintain their stability, fears they will be vulnerable to harm or harming themselves or not knowing what the future holds for you or for them can be very troubling emotions to sit with.

These worries, if left unattended, can certainly keep you up at night, sap your strength or agitate your interactions with those around you. If you are able to recognize that you cannot control the future, you cannot magically force the world to go your way, and you cannot control another person's behavior or their recovery, no matter how much you love them, you are taking a step towards facing the here and now reality.

It may be extremely difficult at times to sort out the line between what your loved one is able to take responsibility for, what they need to take charge of, and where you fit, in your role as caregiver and support. When does your taking control actually hinder them from growing and taking charge of themselves?

So how do you let go when you see your loved one making choices that you feel will have a negative outcome? How do you sort out how to be of help and when that help is interfering with your loved one taking ownership of their own lives and recovery? These are not easy questions to answer, but first start with trying to recognizing the fear, worry, anxiety, and just sit with it, listen to it, and try to sort through what can be done to address your concern. Ask yourself, "Is this something that is happening now or something I imagine may happen?" If you are trying to control the imagined future then bring your attention back to living in the present. Ask yourself, "Who is responsible for addressing this concern? Is this something that I can do something about right now? Is this something that I need to take charge of for my own wellbeing? Is this something that my loved one is responsible for and capable of deciding to care for? Is this something that although painful I must accept and let go of the outcome?"

If you can separate out what you can do something about in the here and now, what you have control over, or what you need to accept or let go of, you are then better able to put your fears and worries to rest.

It takes practice to live in the present. It takes practice sorting out what are your responsibilities and what belongs to another. It takes awareness and practice sorting what is in your control and what isn't. It is this practice of living in the present and clarifying what you can do to take responsibility for your own life that will help keep you steady.



When you recognize there is seemingly so little control you might have to diminish the suffering your loved one experiences, you most likely will face tremendous feelings of grief, sadness, and loss. Your feelings of grief may arise when you realize how their potential may have been impacted by illness. There may be great loss in the changes that have occurred in our relationship with them. There may be overwhelming sadness that your loved one is suffering and you can't relieve them of it.

Grief and sadness are painful and yet the only way to be relieved of this is to feel it. It will pass naturally if you give it recognition. It will pass with recognition and acceptance. Your sadness and your tears are a confirmation of your love and care; confirmation of who and what matters to you. If you can honor your sadness and let it pass in whatever way works, whether through tears or reflection, you are making room for the hope and connection that remains and that is not lost.

We have looked at the necessary skills of listening to and honoring the feelings that come to your attention so you may properly care for yourself and your relationships. Next I think it may help to look at the issue of communication and how you might use your communication skills to foster solid connections, and to use your communication skills to facilitate your personal stability and wellbeing.

Stigma can play an important role in shutting down the lines of communication. Stigma may cause one to resist letting anyone know that they or a family member suffers from mental illness for fear of the perceived consequences. It is an entirely understandable consequence and barrier that you may have cut yourself off or have felt cut off from others as a result of the stigma and challenges of caring for a loved one with mental illness. Remaining silent and cut off from connection and support however, is going to have significant consequences for you and for your loved one.

Let's look at the potential benefits if you can just resist the impulse to remain silent and step around the barriers that you see towards direct communication.

There are so many ways that you may block access to the very support, information, and resources that you need because you are not openly communicating. If you are hiding your struggles then you are alone in them. If you are open, you are opening yourself to the support, information, relief, connections and answers that you may need.

Sure it isn't always easy to openly communicate. It feels like a risk. But, communicating is a risk with the potential of providing healing relief as opposed to the sure confinement and suffering isolation that silence holds. There is hope when you are



connected to others. Have you been keeping your thoughts and feelings to yourself? Have you suffered alone with your burdens out of fear of taking a risk or fear that you would be judged? Have you ever taken a chance and found to your surprise that if you did take the risk to share those difficult feelings, you found relief or comfort just having spoken your mind?

Sharing your experience, communicating your thoughts and feelings may not change the illness, but it does have great potential in changing you. Communicating directly with others will positively influence how connected you feel in your journey and how solid you feel in yourself. Think of a time that you shared openly with another, whether sharing an upset with a friend, communicating a clear limit, making a request directly, or asking directly for help, and remember the feeling or relief, connection, or support that came with it. If you use communication to share your own wishes, feelings, observations, needs or requests without blowing up, without the intent to control someone, then you are more apt to create a bridge with your loved one rather than a barrier.

For example we hear, "The Veteran is hiding out in their bedroom all the time and I am really lonesome." Why not tell them, "I know you're having a hard time but when you are in your room all the time I feel lonesome." Another example may be, "The Veteran just spent our rent money on drugs. I can't scream anymore. I don't know what to say. I give up." So instead of reactively blowing up, what about calming your reaction and share how you feel? For example, "Look it I know I have blown up a million times and it isn't going to help anything, but I don't know what we will do about the rent and I am scared. Do you have a solution?"

Communicating your feelings may not change their behavior or its consequences but you will feel, if you pay attention, the relief in having been direct.

Sometimes we hear Caregivers say there isn't anyone to share with, that family doesn't understand, or friends have distanced themselves, or it's too difficult to get the words out. While clearly connection and communication with others may have its challenges, is it a reality that there is no one to connect with? Difficult to connect, a challenge sure, but think about the connection you have made today by listening in. Think of the Caregiver Support Line as a potential connection. Your Caregiver Support Coordinator, VA staff, your family members or friends that you may not have reached out to, your neighbors, a church group, a community group, a NAMI group, a counselor, a



caregiving peer, Alzheimer's programs, PTSD and Veterans Crisis lines, may also be options. The list is as endless as your imagination.

Well, we have covered a good deal today. We have talked about the steadying power of knowledge to combat the uncertainty and stigma. We have explored some of the potential feelings that may arise and the grounding power of recognizing your feelings and allowing them to inform you about what direction you may take. We have touched on the importance of discerning what is within your control and what is not; sorting through who is responsible and the need at times to simply let go and accept what is in the here and now. We discussed the need to risk stepping out beyond your silence and using your communications to build bridges of connection. Finally, we have challenged you to build the solid connections that we know are there for you and that will support you in your journey ahead.

We hope that this presentation today has been some measure of help returning you back to solid ground and also hope that you know that the Caregiver Support Line is one of many sources of support available to you. We recognize the tremendous sacrifices that you make and the loving devotion that you invest. Hold your heads high and honor, as we do, your mighty efforts.

I hope you found this presentation a worthy use of your time. Thank you for listening. If you are a Caregiver of a Veteran and would like to discuss any of the ideas offered during this presentation, I invite you to contact your local Caregiver Support Coordinator. You may also contact a social worker at the Caregiver Support Line at 855-260-3274. Thank you for all you do.