



## Difficult Conversations & Crisis Situations

For over 65 years the National Multiple Sclerosis Society has been dedicated to improving the quality of life for people with MS and their families. Suicide and assisted suicide are fundamentally inconsistent with this mission.

We are deeply concerned about people with MS and their families and aware of how difficult life with MS can be. While MS is a chronic, incurable condition, it is not fatal. Depression may occur but can be effectively treated. People with MS now have a choice of treatments that can slow the progression of the disease. Symptom management, assistive devices, and support services also can enhance the quality of life for those who have MS.

The National Multiple Sclerosis Society respects autonomy and the right to self-determination. We exist to affirm life and to offer programs that promote positive coping with multiple sclerosis.

While we recognize that a call or contact with a suicidal person evokes many feelings in all of us such as anxiety, fear, sadness, and even ambivalence, we nevertheless, must remain clear and consistent about our goals (as outlined below) as staff and volunteers:

1. Helping the individual explore life-affirming alternatives to suicide.
2. Helping the individual express his/her feelings.
3. Providing an empathic response to those feelings.
4. Assessing potential suicidal behaviors.
5. Making appropriate contact with family/authorities for referral and intervention.

### HANDLING A CRISIS SITUATION

A crisis can come in at any time. A person with MS may come to share a physical or emotionally abusive situation, an eviction from their residence, or even the wish to end their life or someone else's. Or, the entire community may be facing a crisis of some kind. Although a self-help group or an MS Friends connection is not designed to be a crisis center

or an emergency service, it may be the only place a person with MS feels he or she has to talk about the problem. If this is the case, it becomes the role of the Peer Connections volunteer to help the person connect to a more appropriate resource.

This document will include how to handle crisis interactions. It is imperative that you learn this section. We sincerely hope you never will be confronted with this type of situation, but if you are, you need to know what to do. The following information will be very helpful to you and the distressed individual in the rare case that you must respond to an emotional crisis situation and/or critical incident.

**TIP!** Recent research has greatly expanded our understanding of the causes and treatments of depression in MS. Stay current on research by checking the web site regularly for updates. To get started, visit <http://www.nationalmssociety.org/research/index.aspx>.

### Assessing an Emotional Crisis

*Crisis Situations: assessing an emotional crisis  
Dealing with suicidal thoughts or feelings  
Assessing an individual's risk of suicide*

### What to do in a Critical Incident

*What to do in the event of a critical incident?  
Strategies for intervention  
What if the attempt has already been made or is imminent?*

### Abuse & Neglect

*What to do if you suspect or are aware of abuse and/or neglect?*

### Self-Care After an Intervention

#### Assessing an Emotional Crisis

An individual who is frightened or overwhelmed may become very emotional in the course of a conversation that starts out calmly. Sometimes this response is simply a reaction to hearing a friendly, supportive voice, either on the telephone or in a group setting. Having shared a concern, the individual is so relieved to be in contact with someone living with MS that he or she wants to continue talking. The individual may begin to cry and feel very

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embarrassed about this loss of emotional control. In this situation the appropriate response is to remain calm and ask in a matter-of-fact manner if there are other issues or questions he or she would like to talk about with you and/or the group. Tears are normal, and not necessarily a sign of depression or crisis.

If the individual seems to respond to this question and can regain control, you can listen quietly until you have a sense of the problems needing to be addressed. Your calm presence will often be enough to help the individual get into the problem-solving mode with you. Together you may be able to identify a needed resource or referral, or answer questions that have been causing the person a great deal of upset. Most people will respond well to this kind of interaction and be ready to end the call knowing that a helpful connection has been established.

Occasionally, however, you may find that the individual cannot calm down or needs to talk about a problem that seems to require emergency intervention. The individual may even talk about feeling quite desperate and ready to give up. At this point you will need to decide whether the individual seems to be in immediate, life threatening danger or in danger of hurting someone else.

### **Preparing to Respond to an Individual Expressing Suicidal Thoughts or Feelings**

Undoubtedly the most frightening and challenging type of crisis situation involves the person who sounds very depressed or is expressing suicidal thoughts or feelings. This type of individual makes us feel that the person's life is in our hands and that the outcome is totally dependent on what is said or done.

We worry that we won't know what to say or that we will say the wrong thing. We are afraid to question the person about suicidal thoughts or feelings lest we plant a new idea or inadvertently cause the person to act in a self-destructive way. The important thing to remember is that by communicating our willingness to listen we are providing a lifeline to someone in distress. Our most useful tool is our genuine concern. It can enable a person to reconnect with life when he or she had given up all hope of that being possible.

In order to feel prepared to respond to this type of stressful interaction, it helps to:

- Understand the most common reactions experienced by people living with chronic illness
  - Recognize some of the emotional changes caused by the disease process itself
  - Be able to distinguish them from signs and symptoms of a serious depression
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## Common Emotional Reactions to the Disease

Initial reactions to being diagnosed with MS usually include some combination of disbelief, shock, fear and possibly even relief. Some people simply do not believe the diagnosis and continue to search for an explanation for their symptoms that is less difficult to accept. Others may feel shocked into numbness so that they find it difficult to feel anything at all. For those people who have heard only about the most disabling cases of MS, the initial reaction may be fear. Anyone who has lived for months, or years, with unexplained symptoms, or has been told that the problems are all emotional or psychological, may actually feel relieved to finally have an answer. Others may be relieved that their illness isn't a brain tumor or some other fatal disease.

Longer-term reactions to the MS diagnosis gradually emerge as the realities of the illness begin to make themselves known. These reactions tend to be determined by the kinds of symptoms the person is having and the degree to which those symptoms interfere with the person's life. Thus, for someone who works as a store manager or loves to dance, problems with walking might be the most distressing. For an author or teacher, ambulation problems might seem less frightening than cognitive changes involving memory or problem-solving.

In general, however, there are some feelings that everyone with MS tends to experience at one time or another—namely anxiety, sadness or grief, anger and guilt. The important thing to remember is that there is no particular order or progression to these feelings. They are likely to come and go as the disease ebbs and flows.

### Anxiety

One of the hallmarks of MS is its unpredictability. People tend to feel anxious or nervous when they do not know what is going to happen next. Feeling out of control also makes people feel anxious. Neurological changes that affect vision, bladder and bowel control and the ability to walk can feel threatening to any person's sense of control and autonomy.

### Sadness and Grief

Being diagnosed with a chronic illness requires a person to think a bit differently about him- or herself. Almost like a lifetime jigsaw puzzle, one gradually pieces together a self-image. MS is a new piece that somehow needs to be inserted into the puzzle. This kind of change makes people feel sad, and grieving over the lost sense of self is a necessary and important part of building a new self-image that includes MS. Any time a symptom interferes with a

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person's ability to do something that is important to him or her, some of this normal grieving will take place.

## **Anger and Resentment**

Anger and resentment are also common reactions to a chronic, unpredictable disease. People resent the intrusion into their lives of something over which they have so little control. Some wonder what they could have done to deserve this; others find themselves angry at the doctor or at God for letting it happen to them. They may feel anger toward those around them whom they perceive as healthy and free of problems. They may also feel angry at themselves when they cannot do something that they used to be able to do so easily.

## **Guilt**

If and when MS interferes with a person's ability to fulfill various work or family responsibilities, he or she may also experience guilt. No one wants to let down or disappoint family members or colleagues. One of the ongoing challenges for a person living with MS is how to find a comfortable balance between caring for him- or herself and meeting the needs and demands of others.

## **Emotional Changes Caused by the Disease**

### **Mood Swings**

MS can cause structural changes in the brain that increase the risk of abrupt changes in mood and emotional expression. Some mood swings may also be caused by medications, especially high-dose steroids.

Regardless of the cause, abrupt changes in mood can make family life stressful and unpleasant for all concerned. People experiencing these uncomfortable mood swings can be treated very effectively with a combination of psychotherapy and medication.

### **Pseudobulbar Affect**

Pseudobulbar affect, a condition in which brief episodes of laughing and crying can occur without any obvious precipitating event, seems to be associated with lesions in the limbic system, a group of brain structures involved in emotional feeling and expression. Unlike the mood swings described above, the laughing and crying displayed by someone with

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pseudobulbar affect may have nothing to do with how the person is feeling at the time. The laughing or crying may start for no particular reason and then be very difficult to stop.

Pseudobulbar affect can sometimes be helped with certain types of antidepressant medication.

### **Clinical Depression—A Reaction to the Disease and/or Part of the Disease**

In addition to these emotional reactions and changes, individuals with MS can experience significant episodes of depression. In fact, clinical depression is more commonly seen in MS than in the general population or in other chronic disease groups. The evidence suggests that depression in MS can occur as a reaction to the persistent stresses and losses associated with the disease, as well as being a direct result of MS-related changes in the brain. In other words, depression can be a response to, or a symptom of, multiple sclerosis. Regardless of the origins of the symptoms, however, depression can usually be treated effectively with some combination of antidepressant medication and psychotherapy.

Unfortunately, too many individuals with MS do not receive timely or adequate treatment for depression. This may be because they fail to recognize the feelings they are experiencing as depression or because they are reluctant to seek help for emotional problems.

Clinical depression, also known as a major depressive episode, typically includes at least five of the following symptoms, occurring together for the same week period:

- A depressed mood for most of the day every day
- Diminished interest or pleasure in any or all activities
- Significant weight loss or weight gain (more than 5% in a month)
- Significant change in sleeping habits, including much less or much more than usual
- Recurrent thoughts of death or suicide, sometimes including a specific plan for ending one's life, or an actual attempt to do so
- A slowing or speeding up of motor function (i.e. psychomotor retardation or agitation)
- Fatigue or loss of energy nearly every day
- Diminished ability to think or concentrate
- Feelings of worthlessness or excessive or inappropriate guilt (not merely self-reproach or guilt about having an illness)

A review of this list reveals that several of the symptoms of a major depressive episode are relatively common in MS (e.g., motor slowing, fatigue, diminished ability to think or

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concentrate, sleep disturbance and feelings of worthlessness or guilt). This overlapping of symptoms can make it difficult for people, including family members, professionals and individuals with MS themselves, to recognize the presence of a severe depression. As a result, the person with MS may reach a point of crisis before receiving the necessary help for his or her depressive symptoms. It is at this point of crisis that the person may reach out to the National MS Society.

A depressed mood and loss of interest or pleasure in everyday activities are the hallmarks of depression. Suicidal thoughts or feelings may also be present but are not always so. Additionally, the presence of suicidal thoughts or feelings does not necessarily mean that a person is going to act on them. People with a chronic, progressive disease can contemplate the difficulty of their lives, and wish for the struggle to be over, without having any intention of harming themselves or ending their lives. Nevertheless, we cannot ignore the risk of suicide in a seriously depressed person and need to be alert to the verbal and non-verbal cues that are given to us.

Severe depression can be a life-threatening condition because it may include suicidal feelings. One study found that the risk of suicide was 7.5 times higher amongst persons with MS than the general population.

### **Assessing an Individual's Risk of Suicide**

The following guidelines will help you in the event you need to make a suicide assessment and intervention. Although you may go through your entire time as a Peer Connections volunteer without having to deal with this type of interaction, it is important for you to review these guidelines periodically so that you will feel at least somewhat prepared. If you find yourself responding to a statement from someone who seems particularly distraught or distressed, it will be your job to determine if the person is experiencing a life-threatening crisis that requires immediate attention.

As you are talking to the individual, the following are some warning signs to listen for:

**Changes in Behavior:** The person may report losing physical ability in activities or interest in people that he or she previously enjoyed. Formerly outgoing and sociable, the person may have gradually stopped visiting friends, going to meetings or talking on the phone. The person may report emotional exhaustion (e.g., *"I just don't have the energy to be with people anymore."*)

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Changes in Personality: The person may report feeling irritable, anxious or sad while at the same time sounding apathetic about life and the future. He or she may describe a preoccupation with memories of life before MS, and express hopelessness about life ever being “normal” again.

Changes in eating/sleeping habits: Sleep disturbances, including early morning waking, insomnia and excessive sleeping are all common in depression. Since sleep disturbance is also very common in MS, it is important to listen for indications of overall changes in sleep pattern that seem unrelated to physical symptoms such as trips to the bathroom or spasms. Depression can cause eating disturbances as well, including compulsive eating or decreased appetite leading to significant weight loss.

Changes in speech patterns: A depressed person may talk more slowly than usual, as if the energy to keep up speed is gone. Since speech can also be slowed by fatigue and other MS-related neurological changes, it would be important to find out whether the altered speech pattern had been acknowledged by the treating physician as a symptom of the disease.

Feelings of despair or isolation: Feelings of despair or isolation are apparent in the following comments: *“No one can possibly understand how I feel...I will never feel any differently... The world would be better off without me... I am no good to anybody any more... I feel like a drag on my whole family.”* Listen for veiled statements that may suggest suicide/homicide risks.

Drug or alcohol use: The use of substance impairs a person’s impulse control, including the impulse to commit suicide. Alcohol is a depressant. The individual who is using substances is at far greater risk of harming him or herself than the person who uses no substances.

Paradoxically, the risk of suicidal behavior may be greatest at the point when a severe depression begins to lift. A person who has been severely depressed may not have the physical or emotional energy required to act on the suicidal feelings. With the lifting of depression, more energy is available to carry out the act. In addition, some people experience a lifting of severe depression once they have made the decision to end their lives. Therefore, it is important to listen for clues indicative of relief over a decision that has finally been made.

Following are some additional factors to keep in mind when determining a person’s suicide risk:

**Prior attempt(s)** — the number one predictor of a suicide attempt is a prior attempt. The more recent and lethal the prior attempt, the more imminent another attempt might be. A

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prior attempt is a rehearsal. When a person has tried something once, his or her anxiety about trying it again is reduced.

**Suicide in the family** — People who have experienced the suicide of a family member or friend are more likely to attempt suicide themselves. They have come to see suicide as an acceptable way of coping, with the result that their anxiety about it has been lessened.

**Age** — Suicide rates increase with age. Among men, suicides peak after age 45; among women, the rate is highest after age 55.

**Physical Health** — The relationship between illness and suicide is significant. People who are experiencing difficult and uncomfortable health problems tend to be at greater risk for suicidal ideation (thoughts) and behavior.

**Mental Health** — People with depressive disorders, schizophrenia, and other mental disorders are at higher risk for suicide.

**Occupation** — Work, in general, seems to protect against suicide. People who feel productive and useful are less prone to feelings of hopelessness, worthlessness and guilt. Individuals who are unemployed or retired are at higher risk.

**Time of year** — No significant seasonal correlation with suicide has been found. The suicide rate increases slightly during the spring and fall. Contrary to popular belief, however, suicides do not increase during December and holiday seasons.

**Gender** — Although there are obvious exceptions, men and women seem to be emotionally vulnerable in different areas. Men are more vulnerable in performance areas—including work, athletics, and physical stamina. Women are more vulnerable in terms of their relationships—with family members, friends, and coworkers. Although men are three times more likely than women to commit suicide, women are four times more likely to make a suicide attempt.

### **What to do in the event of a critical incident?**

Now that you have been given all this information about suicide and its various risk factors, you are probably asking yourself what you would actually do or say to the person. Unfortunately, there is no perfect script for this kind of difficult and stressful situation, but the following guidelines will be of help.

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1. If you suspect that the individual/caller may be suicidal, it is important to ask the following question: “It sounds as though you’re thinking about suicide. Have you had thoughts about wanting to kill yourself?”

Remember—you are not giving someone the idea or putting a suggestion into the person’s head. If the person had not wanted you to be asking the questions, he or she would not have been likely to make the call in the first place.

2. Find out what’s going on. Try to gather as much information as you can, including the person’s name, address, current location if not at home, and phone number (especially if you are on the phone). Ask the person, “What’s been going on in your life that you’re thinking about suicide.”

Listen for recent losses and changes, as well as anticipated events. If you are concerned that the caller might be at significant and imminent risk, it will be particularly important for you to obtain the person’s phone number. After you have been talking for a while, you might say, “Could you please give me your phone number in case we get disconnected?”

The person may or may not provide you with the number, depending on whether he or she is willing for you to know the information. The actively suicidal individual may be reluctant to be helped or rescued even though he or she has reached out in this time of distress.

3. Find out some history. Ask the person, “Have you ever felt this way before?”

If the answer is yes, ask the following questions: “What was going on at that time in your life? What happened then? What did you do?”

If the caller reports having made a prior suicide attempt, you will want to ask the following: “What did you hope to accomplish at that time? What was the outcome?”

**TIP!** Reference the Society’s [Crisis Support Resources](#) document for different hotline information you can share should the individual has any future suicidal ideation.

People attempt suicide for many different reasons. Most, however, are not seeking death. More frequently, suicide is seen as a way of ending pain, or a way out of helplessness or shame. If the person reports having felt this way before, but never attempted suicide, try to find out what was helpful at that time.

Ask, “What kept you going then? What do you think got you through that difficult time? Could that help you now?”

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4. Most importantly, find out if the person has a plan by asking, “Have you thought about how you would do it? Have you come up with a specific plan?”

Note: It is important to listen between the lines as the person responds to this question. You will glean important information from the quickness of the response as well as from the words the person says. If a person has a thought-out plan, he or she is at significantly greater risk. If there is no specific plan, the suicidal risk is not as imminent.

5. Determine the person’s access to the means necessary for implementing the plan. Once a specific plan has been described to you, it is important to determine whether the person has access to the means with which to carry out that plan. Ask, “Where will you get the pills (gun, knife, car, etc.)?” We want to help the individual limit access to weapons. Ask “Are there weapons in the home?” and if yes, ask “Is there a friend or relative that can remove the weapon from your home momentarily? Is your door unlocked?”

### Strategies for Intervention

If there is a plan as well as ready access to the means for carrying out that plan, the risk of suicide is high and imminent. The most important strategy at this point is to maintain contact with the individual. Your goal, while you keep the person involved and talking, is to assess his or her impulse control. You are trying to determine whether the person can delay acting on the urge to carry out the plan. Try to safety plan with the individual to put the pills, gun, etc. out of reach or sight while you are talking on the phone.

1. If you feel fairly confident about the person’s impulse control and ability to follow through on your recommendations (e.g., you have been able to safety plan with the caller to put the pills or gun, for example, out of sight) encourage the individual to go to their nearest emergency room or call 911. You should also provide them with the website [www.suicidepreventionlifeline.org](http://www.suicidepreventionlifeline.org) or 1-800-273-TALK in case they have any future suicidal ideation.

2. If you are at all concerned about the person’s impulse control (e.g., if the caller has been unwilling to enter into a safety plan with you not to commit suicide) or ability to follow through with the voluntary hospitalization plan, you will need to alert the emergency services. You should **always** inform the individual that you are contacting 911 for a welfare check; “Based on what you have shared with me (or what I am hearing), I’m very concerned for your level of risk. I need to contact the local police to ensure that you stay safe.”

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If there is anyone else in the vicinity at this time, give that person the caller's name and phone number and request that a call be made to the caller's local emergency number (911 or the local number).

If you are completely alone, you will need to call the emergency number yourself. Tell the caller that you are calling for help. If possible, make this call on another telephone set and line so that your connection with the caller is not severed. You might also use the 3-way call line feature on your cell phone. Otherwise, tell the caller that you will call him or her right back. If the caller won't give you their number, address, name or other identifying information to locate him/her, look on your cell phone for the caller ID and give that number to the dispatcher. If caller ID is blocked, call or email your supervisor as provided.

**TIP!** With the caller's area code or zip code, use <http://www.getzips.com> to find out what county they live in. Next, go to <http://www.usacops.com> and find the caller's local police office

3. Discuss any follow-up plan, including asking the person if it is okay for us to call again to see how he or she is doing. This way, Society staff can follow up with them to provide additional support and appropriate resources. Stay on the phone with the individual until first responders arrive.

### **What If the Attempt Has Already Been Made or Is Imminent?**

1. **Stay calm.** If you become too anxious, you may communicate an unwillingness to listen and thereby reinforce the caller's feelings of isolation. You will also need to be thinking clearly.

2. **Find out as much as possible about the actions taken.** The police will want/need as many details about the situation as you can give them, for the benefit of the person in crisis and for their own safety.

- If pills are involved, find out what kind, how many, who prescribed them and when, how many are left, the drug store name, and the prescription number. Any information will be helpful—the more the better.
  - If alcohol and/or drugs are involved, you will need to find out what kind, how much, and over how long a period of time.
  - If a gun is involved, find out where the gun is, what kind of gun it is, and whether it is loaded.
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- If a knife, rope, razor, etc. is involved, you will need to find out where it is, and what the plans are for using it.

3. Gather as much identifying information as you can. You need to find out the caller's name, address, current location, and telephone number. If there is someone else working with you, give that person the caller's identifying information so that he or she can call the local emergency telephone number.

4. Ask the person if the door is unlocked. Explain that you are sending help and will wait on the phone while he or she unlocks the door. This is particularly important if alcohol and/or drugs are involved. In the event that the person loses consciousness, time will be wasted as the police/rescue squad tries to enter the house.

5. Call the police/emergency services. Although you may be worried that the individual will be angered by your telephoning the police/emergency services, this is not usually the case. If, however, you believe that doing so will jeopardize your contact with the caller (i.e., he or she would hang up the phone and not answer when you call back), wait awhile and keep talking to the person. The longer you maintain contact, the better your chances of preventing the suicide. Of course, if alcohol and/or drugs are involved, emergency help must be sent immediately.

*"I am initiating this welfare check because I am concerned about your safety. A welfare check is where a first responder comes out to your home to check on your wellbeing and get you connected to additional resources if appropriate."*

6. Documentation and Follow up Actions- Document your notes about the crisis interaction/call in an email to your staff partner. If a referral was made or if you feel a follow-up call is appropriate, let your staff partner know so that they can arrange a follow-up call. Debrief with your staff partner as soon as possible. This will help you to maintain good boundaries and emotional health. Your staff partner will connect you with the Society's MS Navigator Crisis Team for additional guidance based on the situation you have encountered.

### Abuse and Neglect

One of the most difficult things you can learn is that the person you are helping is being abused or being abusive. Abuse can take many forms—physical, emotional, or sexual. Neglect is failure to provide adequate resources for the provision of a minimal level of care.

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Stress and frustration may lead to abuse and neglect in even the most loving of families. Verbal and physical abuse (by a spouse or partner, by children or parents), as well as neglect, can and do occur regardless of a family's ethnic or socioeconomic background. The issue may come up in your group meetings or in on-to-one conversations with members of your group. Listen for indicators of abuse or neglect.

If you suspect or become aware of an abusive and/or neglectful situation in the home, it is extremely important to discuss your concerns with your staff partner. You may not hear about or recognize such issues until later in the relationship with the person. The Society does not expect you to deal directly with abuse or neglect. It is not your role. However, if you suspect abuse and/or neglect, you can play a significant role in helping the person to move into a safer environment, by taking the following steps:

- Call your staff partner. No more than 24-hours should pass if you suspect that an abuse/neglect situation is happening.
- Debrief with your staff partner as soon as possible. This will help you to maintain good boundaries and emotional health.
- Your staff partner will connect you with the Society's MS Navigator Crisis Team for additional guidance based on the situation you have encountered.

It is natural to feel a sense of guilt when reporting suspected abusive and neglectful situations; however, keep in mind that by reporting your suspicions to your staff partner, you are not seeking to punish the person who is perpetrating the abuse or neglect. You are, instead, taking the first steps to provide help in a bad situation.

### **Self-Care After an Intervention**

It is important not to underestimate the impact this kind of experience will have on you. Helping someone through a suicidal time is likely to arouse many feelings in the helper including anxiety, sadness, fear, and perhaps some despair. Even the most seasoned professionals are shaken by an intervention of this kind. These feelings are normal and to be expected. If you find yourself feeling numb, you are defending yourself from your reactions. It is important to talk about the experience in order to sort out how you feel and get some support for yourself. Carrying the feelings around can be draining and difficult. Therefore, any intervention of this type needs to be followed by a complete debriefing with your staff partner.

It is also important to be aware that suicides sometimes occur despite everyone's best efforts. There are times when the outcome could not have been changed, no matter what was done. In times like these, we all struggle with guilt over not being able to help and feelings of

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inadequacy and frustration in our efforts to do so. In fact, there may be a great deal of similarity between our feelings and those of the person's family such as, sadness, anger, guilt, shame, and a continuous replaying of the event.

If you experience a suicide attempt with one of your callers or group members, please do not go through it alone. As the family needs help, so do all of us. Debrief with your staff partner as soon as possible. This will help you to maintain good boundaries and emotional health. Your staff partner will connect you with the Society's MS Navigator Crisis Team for additional guidance based on the situation you have encountered.

