

National Multiple Sclerosis Society

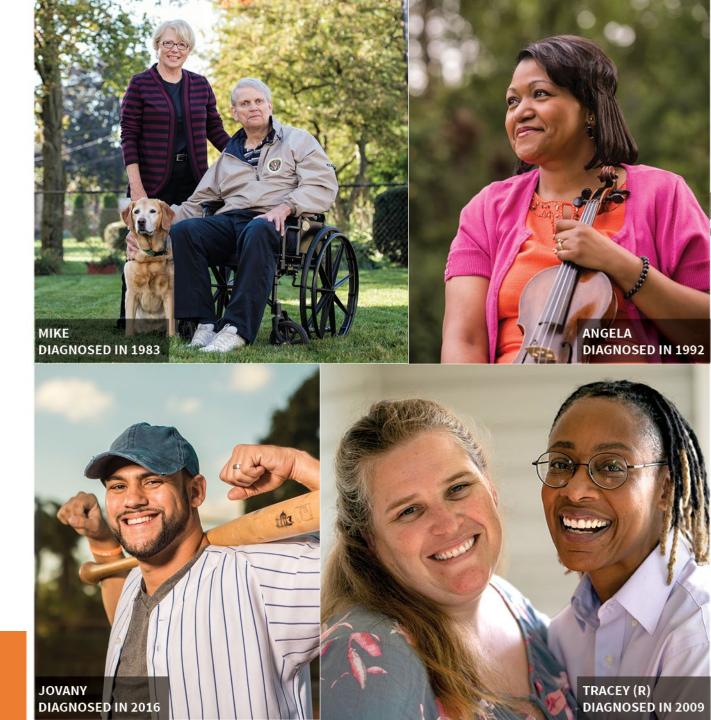
# Peer Connections Volunteer Training

**MSFriends**<sup>®</sup>

### Diversity, Equity and Inclusion

- The National Multiple Sclerosis Society is a movement by and for all people affected by MS.
- Our voices and actions reflect diversity, equity and inclusion.
- We welcome diverse perspectives.
- We actively seek out and embrace differences.
- We want everyone to feel respected and be empowered to bring their whole selves to ensure we make the best decisions to achieve our vision.





### **Inclusion Policy**

At the National MS Society, we are committed to embedding diversity, equity and inclusion in everything we do, and we have zero tolerance of any ill treatment towards any person in the MS movement.

#### Everyone who shares our vision of a world free of MS is welcome here. Hatred is not.

This work is a journey requiring commitment, accountability, transparency and courage. We know it will not be easy, but we are going to do it anyway. We are not striving for perfection, only intention and action as we move forward. We extend grace and empathy to everyone who wants to join us on this journey of learning, growth and change. However, we will not tolerate acts of harassment and discrimination.

The National MS Society is here for **every** person with MS — we always will be — until we find a cure. We embrace and are committed to bringing our entire MS community together, representative of all the dimensions of diversity, so that everyone feels at home and supported by their National MS Society.



### **Community Disclaimer for Peer Connections Participation**

The National MS Society respects the rights of people with MS to obtain any and all information they want related to MS including information on wellness, medical treatments or complementary therapies, products and services. The information shared during community connections does not necessarily reflect the views or official position of the National Multiple Sclerosis Society, nor carry the endorsement or support of the Society.

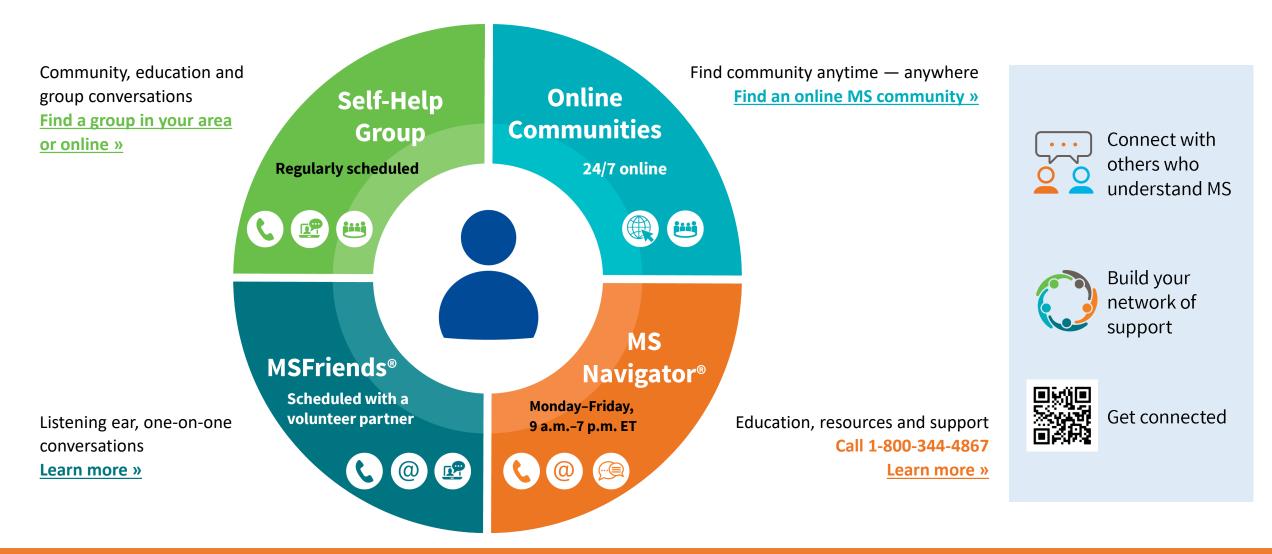
By choosing to participate in National MS Society-governed self-help groups, MSFriends<sup>®</sup> paired connections, and social media and online communities, you are agreeing that the Society can contact you directly in response to any posts or content that suggests risk to self and/or others. The Society reserves the right to contact you in the event that "at risk" statements or content occur.

To protect your privacy and the privacy of others, please do not record, take screenshots, or share personal information with anyone other than your staff partner.

For specific medical advice, contact your physician. For the opinion of the National Medical Advisory Committee of the National MS Society on any therapy, treatment or product, please contact an MS Navigator at 1-800-344-4867 or visit our website at <u>www.nationalMSsociety.org</u>.



### **Connection Opportunities**





### **MSFriends**<sup>®</sup>

Connects individuals one-on-one for meaningful interactions based on shared lived experiences.

#### Who are MSFriends volunteers?

• Trained, empathetic listeners

#### Who can participate in MSFriends?

Anyone with a connection to MS

#### **MSFriends provides emotional support through...**

- Reducing social isolation
- Facilitating meaningful connections based on shared, lived experiences





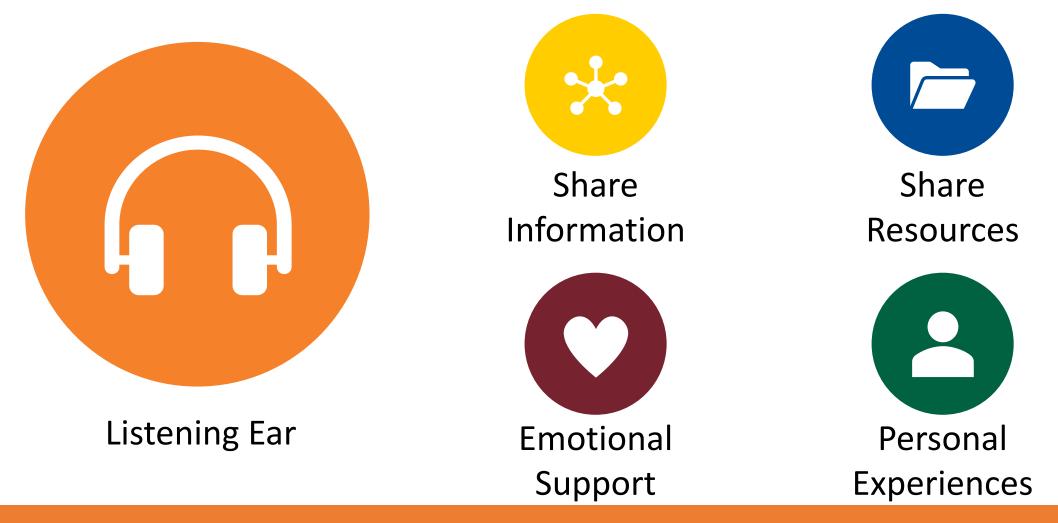
# Reflection

"Understand that most [participants are wanting] to talk, and you have to remember to listen without judgement or advice or telling your story, unless they ask for it."



**Together We Are Stronger.** 

### **MSFriends<sup>®</sup> Connections**





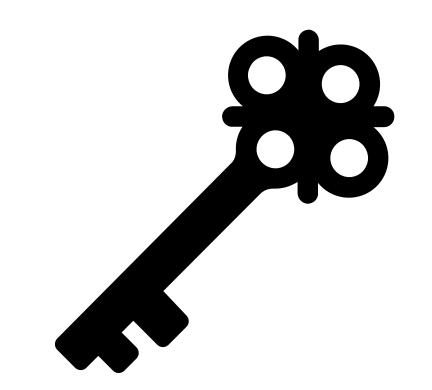
### **Typical MSFriends Conversations**

#### **Topics generally include**

- Family and social dynamics
- Symptom management, including physical changes, cognition, and mood
- Changes to everyday life
- Adapting to a new normal



### **Keys to Active Listening**



#### Components

- Restating
- Questioning
- Summarizing
- Reflecting & Validating Feelings



## **Demonstrating Good Listening**



### **General Techniques:**

- Asking follow-up questions
  - Generally: "What happened next?" or "What else?"
  - Specifically, about the topic
- Staying with the present point
- Observing both the facts and feelings

### Phone or Video Calls:

- Showing interest through tone of voice
- Convey interest by saying things like "Yes" or "I hear what you're saying"



### Communication

#### **Verbal Cues**

- Tone of Voice
- Hesitancy or Rapid Pacing
- Spacing of Words or Sighs
- Silence



# "I'm having trouble hearing, could you...(repeat that or speak slower/louder)?"



## Reflection

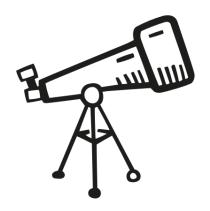
### "Be patient, as each [person] comes from a different place along the MS road."



**Together We Are Stronger.** 



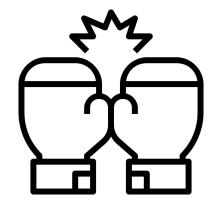
### **Interpersonal Skills**



Self-Awareness & Personal Limitations

Empathy

#### **Building Trust**



Judgement

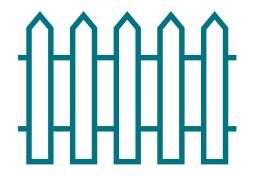
Managing Challenging Conversations

Professionalism



### **Establishing Boundaries**

- Identify your "hot topics"
  - What are you comfortable listening to?
  - What are you willing to share?
- Choose your role in the conversation: Listening ear or conversation contributor?
  - "I don't have anything to contribute to this topic, but I'm here to listen"
- Use active listening skills
- Do not give medical advice- not our role
- Tell staff if someone makes "at risk" statements





### **Emotional Responses**

#### **Positive Responses:**

- Relief
- Validation

#### **Challenging Responses:**

- Anxiety
- Grief
- Anger
- Depression



MSFriends volunteers provide emotional help and support but are not a substitute for professional mental health services.



### **Solution Focused Conversations**



Focus on possible solutions, not the problem itself

"What has worked for you in the past when you were feeling <a certain emotion, e.g., afraid and uncertain)?"



**Jamie:** Hello, Jessie. How are you today?

**Jessie:** Not good. I've been depressed lately. My MS is acting up and I'm feeling tired all the time. My husband and daughter just don't get it.

Jamie: That sounds awful. I can understand why you have been feeling depressed.

- Jessie: Yeah. It has been so bad that I really haven't been able to go to work. I stayed home three days last week and haven't been able to do much around the house. My family should know that I'm exhausted. My daughter told me that I look fine. I think she thinks I'm lazy.
- Jamie: Those must have been some very depressing days—missing work and feeling that your family doesn't understand.
- Jessie: I spent most of the day in bed or on the sofa. It was really too much for me to deal with.

The conversation is focused on the problem. You can almost feel Jessie getting more and more depressed as they are reminded of a difficult week.



**Jamie:** Hello, Jessie. How are you today?

- Jessie: Not good. I've been depressed lately. My MS is acting up and I'm feeling tired all the time. My husband and daughter just don't get it.
- Jamie: That sounds very frustrating. Have there been days that you've felt less depressed than others?
- Jessie: A few. I was able to keep focused and get some work done from home. I also read a book with my daughter and helped with her homework which we enjoyed.
- Jamie: What do you think made those days better?
- Jessie: I'm not really sure. To be honest, I think it was my attitude toward the day. I was just as tired, but I was determined not to let it ruin the day. I also told my family in the morning that it was a high fatigue day, and that seemed to help. They said they were glad that I told them.

Jamie acknowledged Jessie's feelings, but then moved focus on the days that didn't feel as difficult. That subtle change in conversation <u>helped Jessie</u> to see what they could do differently (solutions) to manage their distress.



### How to Manage Hard Conversations

#### **Uncomfortable Topics & Setting Boundaries**

- "I don't feel comfortable talking about that, could we go back to..."
- "That's not something I share about, but I'm here to listen."

#### **Negative & Abusive Language**

- "We don't use that language in our conversations."
- Offer a warning and a chance to self-correct
- If language continues, end conversation and contact Peer Connection Resource Team for support



# Reflection



"I think by far the most important thing I'd tell a new [volunteer] is to 'read the room'. First try and figure out what the [participant] needs most. Are they venting or looking for advice/ideas? Are they in a fragile state of mind?"

### $\bullet \bullet \bullet$

"Be Present - a lot can picked up from someone by what or how something is said or not said. We are the listener and need to be able to provide our undivided attention to the [participant]."

**Together We Are Stronger.** 

# **MSFriends Program Details**



**Together We Are Stronger.** 

### **Pairing Process**



- 1. Participant completes an **application** (online or over the phone).
- 2. Staff team **matches** up the participant with a well-suited volunteer.
- 3. Participant and volunteer are **introduced** via email.
- 4. The pair **meets** for the first time.
  - a. Get to know each other
  - b. Choose how to connect: phone, video call, or email
  - c. Choose connection cadence (e.g. Tuesdays at 2pm for 30 minutes)
- 5. Pairs **connect** for up to 6 months on their agreed upon cadence.
- 6. Volunteer **notifies** the Resource Team when the connection wraps up.



### **MSFriends Boundaries**



#### **Phone Call**

Call from a blocked number (\*67)



#### Email

- Utilize an anonymous email address
  - (e.g., firstname.msfriend@gmail.com)
- Don't put personal information in your email address
  - (e.g., your city, birthday or last name)



#### Video Call

- Set up your camera to have a solid wall behind you
- Ensure you're in a well lit, quiet place for your conversations



# Reflection



On the importance of validation and active listening:

- "Effective listening and hitting on the points that they want to talk about.
- Being able to make a synopsis at the end of the conversation.
- Being able to say [the synopsis] back to them at the beginning of the next conversation.
- Reminding them of what they reached out for initially."

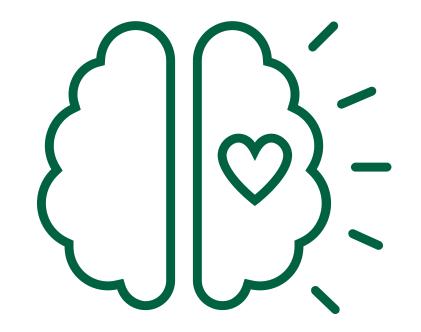
## Support for MSFriends<sup>®</sup> Volunteers

#### Self Care & Support

- Every conversation will be different
- Don't take your work home

#### **National MS Society Support**

- Peer Connections Resource Team
- MSFriends<sup>®</sup> monthly Zoom calls
  - Ongoing peer-support for you
- Peer Connections Volunteer Facebook Group
- News You Can Use monthly newsletter





### National MS Society Resources

**Peer Connections Resource Team:** <u>peerconnections@nmss.org</u>

**Connections Volunteer Website:** 

www.nationalMSsociety.org/PeerConnectionsVolunteers

**MS Navigators**<sup>®</sup>:

Phone: 1-800-344-4867 Online chat: <u>www.nationalMSsociety.org</u> Email: <u>contactUsNMSS@nmss.org</u>

#### **Find Doctors and Resources:**

www.nationalmssociety.org/Resources-Support/Find-Doctors-Resources

#### **Facebook Groups: Peer Connections Volunteers & MSFriends Volunteer Networking**



# Reflection



"Every couple of weeks there's something new I learn. I've had MS for 20+ years and there is always something new to learn."

"I like talking to people on the phone and listening to them. I like feeling that I'm helping and I feel as though they help me too. Sometimes, I learn something new from listening to them."

**Together We Are Stronger.** 



National Multiple Sclerosis Society

# Thank you!

This concludes the MSFriends training.

Reach out to PeerConnections@nmss.org with additional questions