

# PEER Link

Patient Education & Empowerment Resource



PEER Link is a one-to-one support program that offers amyloidosis patients and caregivers the opportunity to connect with a trained peer mentor around a shared experience.

## OUR FOCUS

**IMPROVING**  
the speed and  
accuracy of  
diagnosis

**INCREASING**  
our understanding  
of the genetics,  
biology and  
natural history  
of amyloidosis  
to identify new  
treatments

**ACCELERATING**  
regulatory  
approval and  
reimbursement  
of effective  
treatments for  
patients

**ENHANCING**  
care and quality  
of life of patients  
and caregivers  
throughout their  
amyloidosis  
journey

# Amyloidosis Research Consortium – PEER Link

**ENHANCING**  
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# Mentor Training Goals

1

## Set the Stage

- Benefits of Peer Support
- Role of a Peer Mentor

2

## Build Mentoring Skills

- Communication
- Accepting Differences
- Use of Your Own Story
- Self Care

3

## Explore Resources

- ARC Materials
- PEER Link Resource Lists
- Program Support
- Referral Protocols

4

## Set Expectations

- Program Structure
- Timeline and Next Steps

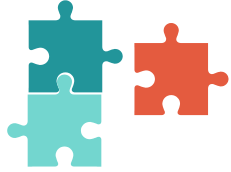
# Peer Support



“To know the road ahead, ask those on the way back.”

- Chinese Proverb

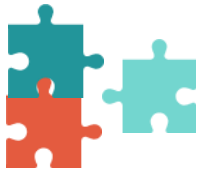
# Benefits of Peer Support



Greater well-being and quality of life



Improved skills and confidence to manage health and other challenges

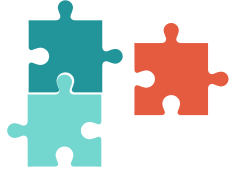


Reduced isolation



Increased hope

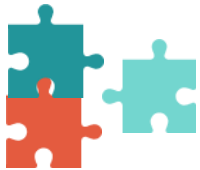
# Benefits of Peer Support for both mentors and peers



Greater well-being and quality of life



Improved skills and confidence to manage health and other challenges



Reduced isolation



Increased hope

# Role of a Peer Mentor



“A mentor is someone who allows you to see the hope inside yourself.”

- Oprah Winfrey



## Peer Mentor

Knowledge from personal experience

Support via shared experience



## Professional

Knowledge from education and training

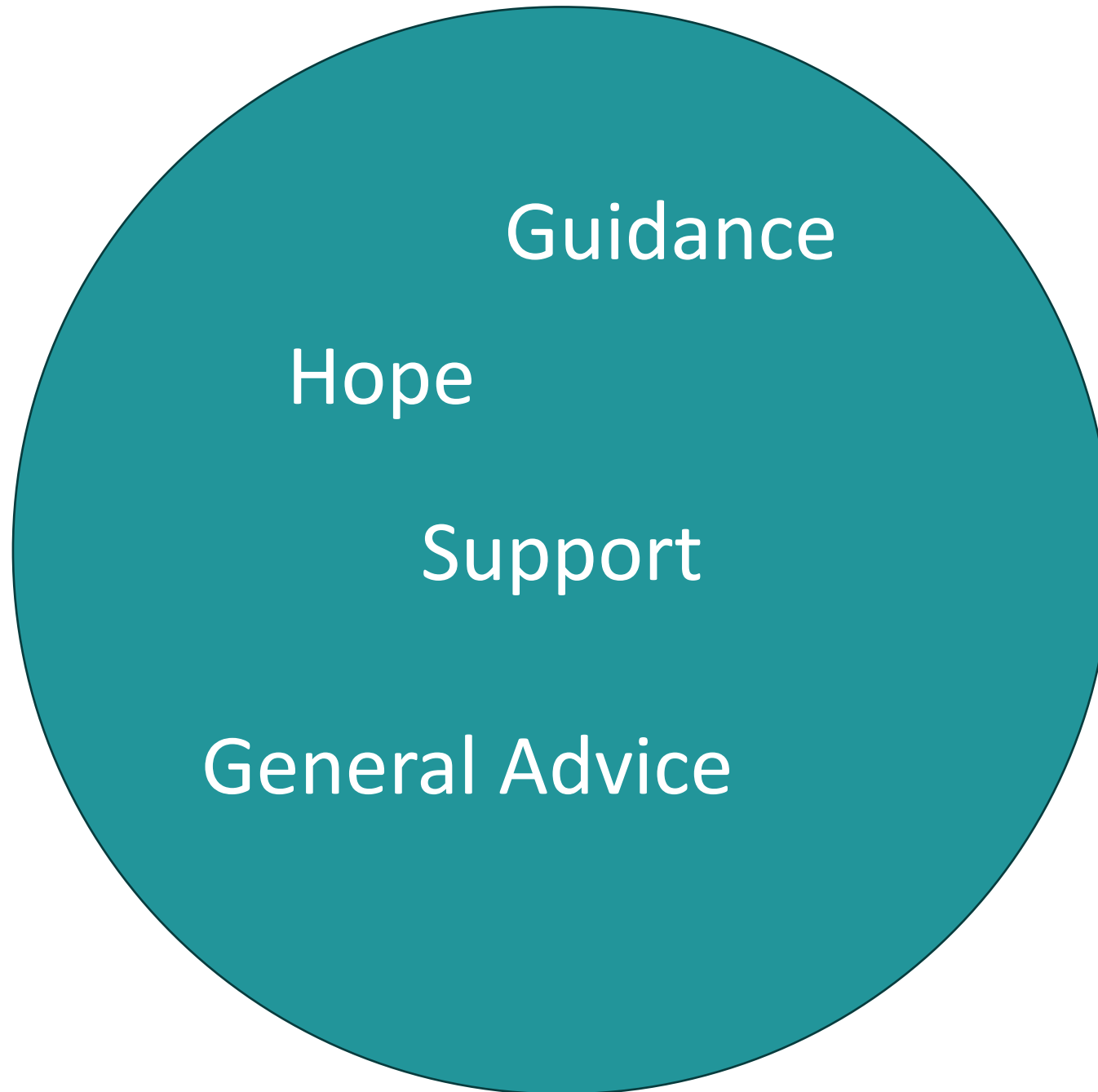
Support via counseling and problem solving

Outside Scope of  
Mentorship

Inside Scope of  
Mentorship

Mental Health  
Assessment

Decision  
Making



Medical  
Advice

Promises

24/7 Hotline

Sounding  
Board

Problem  
Fixer

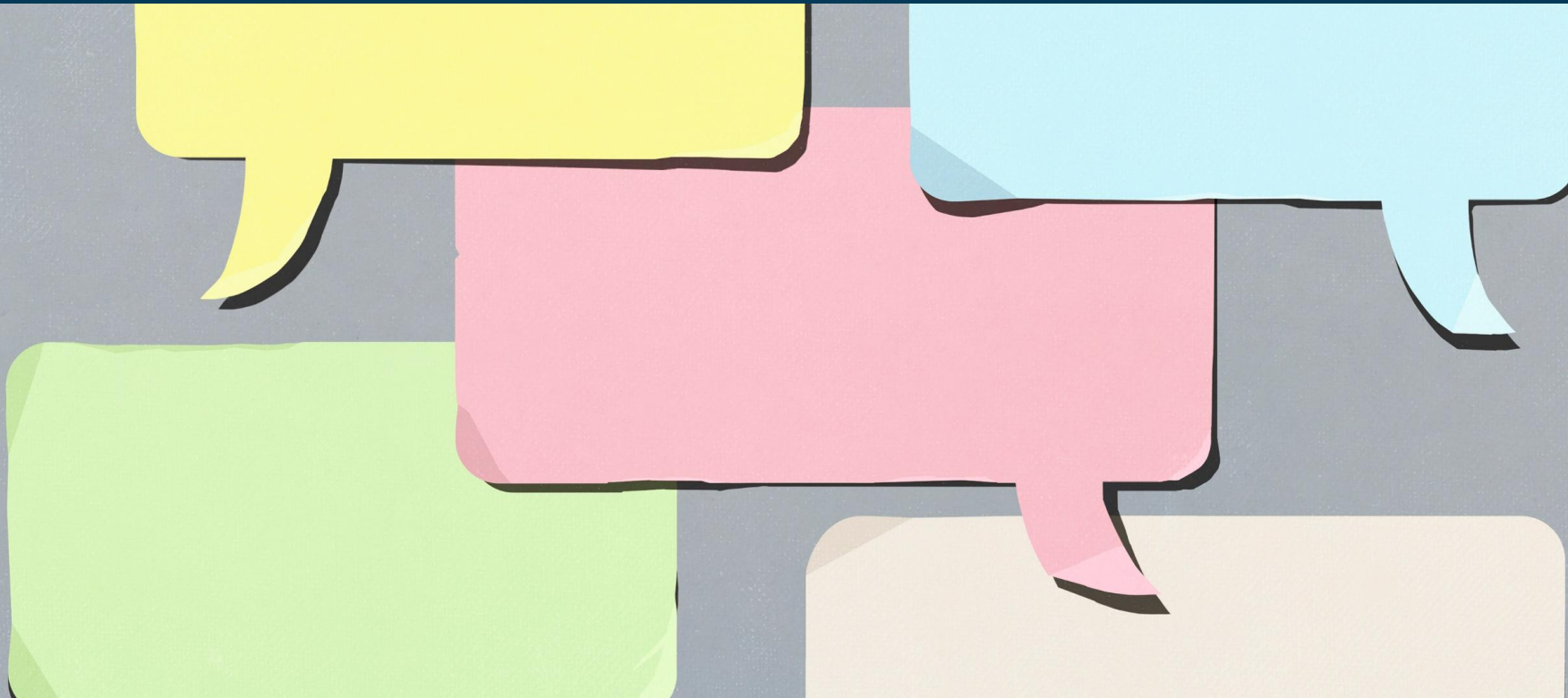
Dumping  
Ground

Listening Ear

Someone Who's  
"Been There"

Doctor/  
Therapist

# Mentoring Skills



“Empathy is the foundation of effective communication, allowing us to connect with others on a deeper level.”

- Marshall B. Rosenberg

# Dr. Brene Brown on Empathy



# Four Qualities of Empathy



## Perspective Taking

Put yourself in the other person's shoes.



## Staying out of Judgement

Focus on listening, not evaluating.



## Recognizing Emotion

Think of a time you have felt similarly.



## Communicating

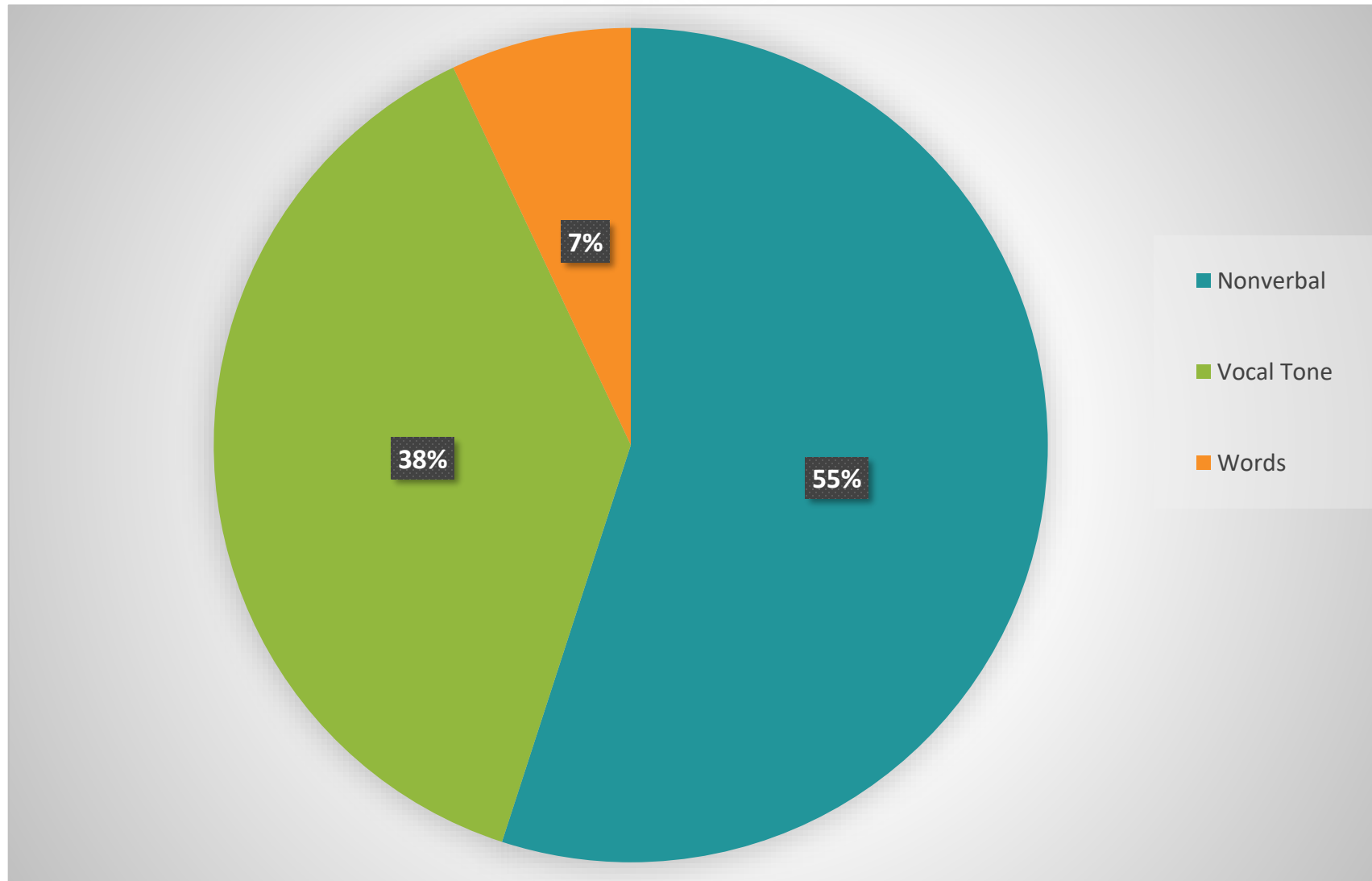
Share understanding to build trust and connection.

# Communication Skills: Active Listening

Avoid interrupting

Use verbal and nonverbal cues to encourage your peer to share

# Communication Composition



# Communication Skills: Active Listening

Paraphrase and reflect back

Ask open ended questions

# Open Ended Questions

- How are you feeling right now?
- Would you like to talk about it?
- Where would you like to begin?
- How do you feel now about...?
- How would you like things to be?
- What have you thought of?
- How do you see things changing?
- What would you like to do about...?
- What can you think of?
- What's most important for you right now?

# Support and Partnership Skills

Build rapport

Compliment effort

Reassure when appropriate

Set expectations

# Conversation Starters

- Where do you live? Where did you grow up?
- Describe yourself in three words.
- What are your favorite hobbies, movies, books, or music?
- Tell me about your family.
- What is/was your dream job?
- Where did you go on your last vacation?
- What is your proudest achievement?
- What are the top three items on your bucket list?
- Who would be the three guests at your dinner table?
- What are three things that make you happy?

# Accepting Differences



"We all should know that diversity makes for a rich tapestry, and we must understand that all the threads of the tapestry are equal in value."

— Maya Angelou

# Accepting Differences

Accept that we all have biases

Cultivate self-awareness

Be open to new experiences

Educate yourself

Be flexible

(Adapted from Johns Hopkins University)

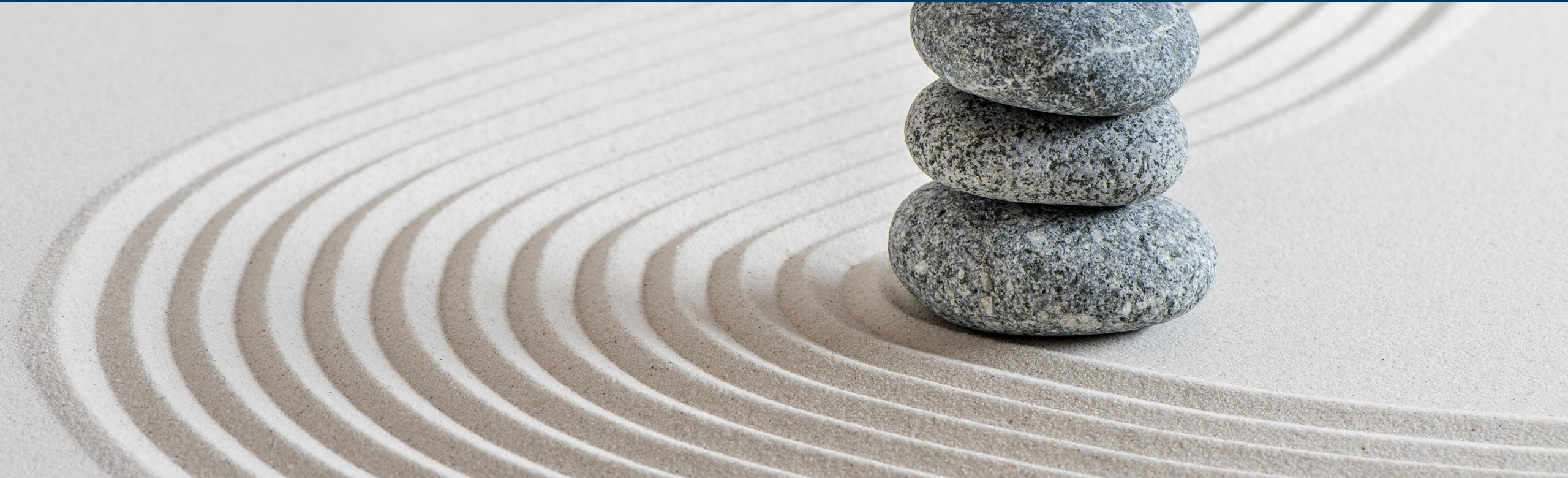
# Use of Your Own Story



“The purpose of a storyteller is not to tell you how to think, but to give you questions to think upon.”

— Brandon Sanderson

# Self Care



“When you say ‘yes’ to others make sure you are not saying ‘no’ to yourself.”

– Paulo Coelho

# Self Care



Maintain balance in your own life. Set boundaries.



You cannot help everyone. Think about who else in your program can help your peer. Is it time to reach out to the PEER Link team?



Take care of your own health. Think about what activities you enjoy and try to regularly take time for those. Seek peer support for yourself.



Take care of your own mental health. Identify your emotional triggers. Seek support if needed.



Monitor yourself. Recognize your limits. Pace yourself.

# Resources



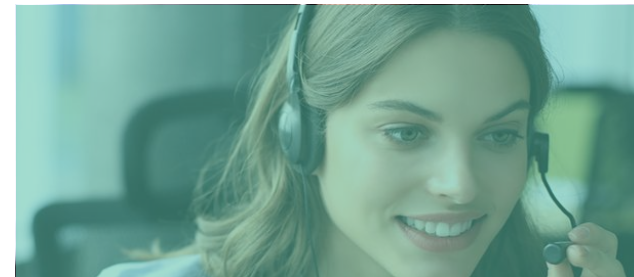
PEER Link will provide a “cheat sheet” with links to ARC materials and external resources.  
[support@arci.org](mailto:support@arci.org)

# ARC Patient Programs

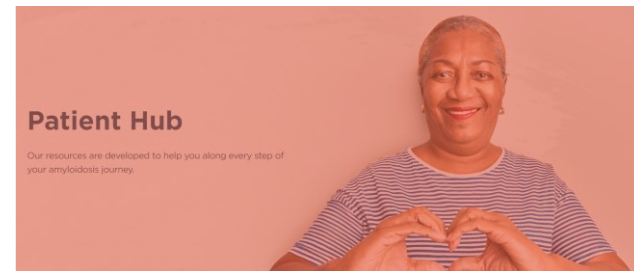
ARC Talks: Educational webinars by leading experts in amyloidosis provide the most current information and an opportunity for patients to have questions answered.



Patient Support: Dedicated staff respond to inquiries and requests from patients and caregivers, connecting them with resources and additional support.



Resource Hub: The ARC website provides an array of educational and informational materials including disease booklets and patient videos.



# My Amyloidosis Pathfinder



My Amyloidosis Pathfinder (MAP) provides information about treatment centers and clinical trials.  
[www.myamyloidosispathfinder.org](http://www.myamyloidosispathfinder.org)

# When to Refer



You will receive written information on when, how, and where to refer people to services.  
[support@arci.org](mailto:support@arci.org)

# When to Refer



## Practical Assistance

[support@arci.org](mailto:support@arci.org)



## Medical Information

Direct them to their doctor



## Mental Health Concerns

Call 988

# When to Refer

Don't try to fix problems (insurance, finances, lack of food, shelter, gas).

Don't take responsibility for your peer's behavior (medication, diet, exercise appointments, lifestyle choices).

Don't try to treat your peer's mental health issues or disease state.

Seek help for mental health concerns, destructive behavior, threat of harm to self or others.

# Symptoms of Depression and Anxiety

Mood changes – sadness, irritability, hopelessness

Sleep changes – too much or too little

Appetite changes – weight gain or loss

Physical problems, difficulty concentrating

# When to Refer for Mental Health Concerns

Symptoms are causing significant distress or impairment in functioning

Symptoms are affecting relationships, work, or hobbies

Symptoms have persisted for a long time

Thoughts of self-harm or suicide

# Expectations and Next Steps



# Peer Mentors Agree to



Maintain  
Confidentiality



Participate in a  
3 Month Match



Connect with Peer  
Every 2 Weeks

# Next Steps

- Receive written materials and sign contract.
- Receive match information and reach out to your peer.
- Connect with your peer every few weeks.
- Receive check-in emails and respond as needed.
  
- Complete end of match survey.
- Indicate whether you'd like to be matched with a new peer, take a break, or leave the program.

# Questions?



# Thank You





Amyloidosis  
Research  
Consortium