

The Angioma Alliance

Peer Partner Manual

Section I

The Role of Peer Partners

“There I was, riding a roller coaster I did not remember buying a ticket for. I was told I had a cavernous angioma, told to strap in and hold on. Clink, Clank, up the first hill I started. “Get me off of this ride!” I shouted. “I don’t want this thing in my brain wreaking havoc on my body.” As I came down the first hill I lost not only my stomach but my dreams for my future as well. I closed my eyes in shock as the ride whipped me about. I felt anguish, fear, and anger overwhelming me. When I got the courage to open my eyes, I realized that there was someone in the seat next to me – another person with a cavernous angioma. She said, “Hold my hand and I will help you get through this ride.” With my peer partner’s support I learned that I was not the only one on this roller coaster. She listened to my fears and began to show me how to survive this ride as well as the others I would face. As we exited the roller coaster hand-in-hand, I knew that for now I would be okay and that she would strap in next to me the next time I got on the roller coaster.”

Adapted from writing by: Dana Yarbrough, Parent to Parent of Virginia

Peer support is based on the philosophy that the person who can really understand you is the person who has been there too. Peer Support Volunteers help others facing life circumstances similar to their own.

Some people prefer to handle life circumstances on their own; others turn to family, friends, and professionals for support. Those who want assistance may discover another resource – peer support.

A Peer Support Volunteer offers a unique and valuable service to others struggling to learn to live with one or more cavernous angiomas. The Volunteer is directly affected by cavernous angiomas and wants to share his or her experiences with others. By offering a friendly ear, the Volunteer will help ease the fear and isolation that may come with a diagnosis of cavernous angioma(s).

The goal of peer support is to link people who have experienced the challenges of living with a cavernous angioma(s) with others facing similar difficulties. Depending on the situation, a match may require a single exchange or follow-up contacts over an extended period of time. Contacts may be by phone, email or in person should the two people be geographically close.

To act as a peer support helper, a person must keep his or her problems out of the relationship. The helper must be willing to keep all information in the strictest confidence as well as refrain from giving advice (Poyadue, 1990). Peer support does not replace professional help. Trained peer helpers need to have a clear idea of their role in providing support to individuals and families and not attempt to provide psychotherapy or take the place of a physician. The peer supporter should know that, even for individuals affected by the same genetic condition, everyone’s medical needs are unique.

“The peer helper must recognize that he or she cannot change a family diagnosis or eliminate their grief. The helper cannot provide daily support to a family or solve their financial problems. The peer helper should not allow a family to drain them so that they can no longer listen, empathize and care. The peer helper should not feel guilty or inadequate if the person they are partnered with cannot adjust to their new medical situation or if their offer of help is rejected” (Trombino and Bernhardt, 1990).

Peer support is not counseling or therapy. It is not a friendship program, although a friendship may grow from the peer support relationship. It is an opportunity to offer support to others learning to live with a cavernous angioma(s).

The Peer Support Volunteer:

- Respects confidentiality
- Respects others
- Is non-judgmental
- Listens to the concerns of others
- Communicates interest and concern for others
- Provides support, encouragement, and information as someone who has been through the experience and found the personal resources to move on
- Suggests contact with Angioma Alliance for information on programs and services
- Works with the designated supervisor and other Peer Support Volunteers
- Follows the position description of the Peer Support Volunteer

The Peer Support Volunteer has the opportunity to:

- Meet new people
- Improve communication skills
- Increase self-confidence and self-awareness
- Help others
- Have temporary respite from his or her personal situation

It is one of the most beautiful compensations in life that no man can sincerely help another without helping himself. – Ralph Emerson

The Peer Support Volunteer does not:

- Provide counseling or therapy
- Take on another’s problems as their own
- Lend money
- Give medical advice
- Do personal favors
- Provide transportation
- Come up with all the answers

Adapted from the Kidney foundation of Canada’s Peer Support Guide, 2003.

“Somewhere, someone is looking for exactly what you have to offer.” – Louise L. Hay

The Match Process

The coordinator will get a request for a peer partner. The person requesting a partner will fill out a request form that gives Angioma Alliance information to help us make a suitable match, plus an authorization for us to release their name and contact information to a peer partner. Once the form is returned, the coordinator will make a match. The location of the angioma(s), disabilities of the person, whether the person is requesting a match for themselves or if they are a parent with an affected child, whether they have had surgery, their preferred means of communication (phone or email), etc. will be considered to ensure the best match possible. Once a potential match is found, the coordinator will contact the peer partner to see if she/he is available. When you are contacted:

1. Please say no if it is not a good time for you. We all have times when we only have enough energy for ourselves. You always have the right to refuse a match.
2. If you accept the match, the coordinator will give you information about the person. (Remember: keep the information confidential). The coordinator will give your name, phone number and email address to the person only if you give permission.
3. Please contact the person as soon as possible – within 48 hours. Waiting for a call can seem like an eternity for the newly referred person. Allow plenty of time for the initial phone call.
4. If you are unable to reach the person, please contact the coordinator to verify the correct phone number/email address, or she can contact the person to see if there has been a change of heart.
5. Once you have reached the person, contact her/him again in a few days to see how they are doing. Contact the program coordinator to let them know how the match is going. After that, try to communicate by email with the coordinator every two weeks or so to let us know how the match is going. Please call or email immediately if any questions or concerns arise during the match period. Your commitment to the match is usually about one-two months.
6. If the relationship is not going well at any time during or after the match period, please contact the coordinator immediately for assistance.
7. There are a number of different directions your relationship with your peer can go:
 - a. Your relationship may come to a natural ending where your peer is adjusting back into their life and no longer needs your support and communication.
 - b. You may “hit it off” and decide to stay in touch (with less frequency) at the end of your match period.
 - c. Your relationship does not work out. It is quite possible that your peer may need a level of support that only a professional can provide. Try to know your limits, suggest counseling, and contact the coordinator if you need help or need to discontinue working with someone.
8. At this point, your commitment to the match is complete.

Section II

Communication Skills

One of the first questions a new partner may ask you is “How are you (or your child); are you okay?” You need to decide how much you want to share. By sharing your story, photos, etc. you are letting the person know the experience is a shared one. You are showing acceptance of their feelings. You are showing understanding of their concerns. Sharing helps them to see past the initial days when their own situation seems so overwhelming.

Hold in confidence what a partner may tell you. It is okay to discuss situations with each other, but please do not mention names (unless you are talking to your program coordinator). When discussing doctors or hospitals, please do not make critical or disparaging comments – the same team of medical professionals may be treating your partner! Doctors handle situations differently and medical routines vary from one patient to another, so don’t compare notes.

Overall, remember, you are not this person’s professional counselor. If the person shares information with you that they are hesitant to share with the professional, encourage them to share that information with their doctor, therapist, teacher, etc. Consult your local program coordinator if you feel the situation is serious and the person cannot be persuaded to discuss their problem with professionals.

Do’s and Don’ts

Do’s:

- listen and give feedback when asked
- write down what the person says
- answer questions
- ask them what is on their mind
- ask them to clarify any specific problem
- allow emotions (including crying)
- speak softer as they speak louder
- respect their need for privacy
- go slowly
- check back with them if they don’t call
- respect lifestyle if different from yours

Don’ts

- argue
- defend or become defensive
- promise things you can’t produce
- probe for information not given
- interject while the person is speaking
- raise your voice
- belittle or minimize their problem
- make moral judgments
- give advice
- be afraid of silence
- push acceptance

Sharing Personal Stories

Sharing personal experiences can be useful:

- introducing yourself to another affected person
- letting others know they are not alone
- helping others discuss a problem they may find it difficult to ask about
- showing acceptance of a person’s feelings and to build a rapport
- reinforcing another person’s decisions or actions

It is very important to stress that everyone is different and will find unique answers to their own problems. When using your own experience as an example, you might say, “This worked for me, but I

cannot say that it will work for you. I just want to share it with you because it might be something you have not thought of yet.”

In sharing personal stories, it is important to remember that no one can know exactly how another person is feeling. Instead of saying, “I know how you feel,” say, “I have had similar feelings myself.”

Some Helpful Things to Say

- It’s okay to feel sad. You have a right to feel that way.
- You are not alone. I will be here for you.
- What can I do to help sort out the situation?
- There are some resources that might be able to help you.
- I don’t have all the answers, but maybe I can make a few suggestions.
- Above all, remember you know yourself (or your child) the best.
- Love and enjoy yourself, and your family.

Giving Advice

Peer partners are often asked for advice. However, giving advice can sometimes do more harm than good. Although you may feel that you have a lot of advice to give, there are dangers associated with giving advice.

Dangers associated with giving advice:

- You may be offering a solution before you know the real issue
- You may not have all the information to understand the problem
- The person may need more time to work though and share their feelings before working on a solution
- Giving advice may prevent the person from developing their own answers
- Getting advice may make some people feel patronized

One of your goals as a peer partner is to empower the person to make their own choices.

Instead of giving advice:

- Find out more information (“I know you are really upset about this, but maybe you can tell me more about what you are thinking.”)
- Offer your own similar experience
- Refer the person to a professional
- Simply say, “I don’t know.”
- Be quiet! Just listening will help the other person feel supported and better able to find solutions to their own problems.

Note: These sections were adapted from Support Parent Training: Facilitator’s Guide, 1994

Skills of Non-Written Communications

1. **Attending:** The ability to give full, undivided attention to the person.
2. **Listening:** The ability to hear all the words and phrases the person uses.
3. **Responding:** The ability to communicate to the person an accurate and complete understanding of the feelings, thoughts, and experiences the person has attempted to communicate to you non-verbally and verbally.

1. **Attending Skills:** Attending is the keystone of effective non-written communication.

Giving this person your full, undivided attention:

- indicates a willingness to interact
- enhances concentration
- promotes a sense of security and openness
- enhances a sense of personal worth

2. **Listening Skills:** Good listening is an active and creative skill.

Listening allows you to manage the situation.

- you learn what a person feels, thinks, and experiences
- you subordinate your own feelings, thoughts, or experiences
- you can better understand the person and the information they are providing you

Listening has a positive effect on the person:

- you demonstrate respect and concern for the person
- you demonstrate a willingness to learn what the person is feeling, thinking, and experiencing
- you demonstrate a willingness to help the person sort through a wide array of feelings, thoughts, and experiences

3. **Responding Skills:** Responding appropriately. The ability to communicate to the person an accurate and complete understanding of the feelings, thoughts, and experiences the person has attempted to communicate to you non-verbally and verbally.

- encourages continued communication
- creates a sense of worth in the person
- allows the person to explore further what he/she is feeling
- acknowledges the unique world of the person
- focuses the communication on the person's world, not yours
- demonstrates respect for the uniqueness of the person
- creates a sense of caring about the person
- elicits more information from the person

Skills of Non-Written Communications section adapted from Parent to Parent – February 1995 – Greater Richmond Metro Area. Jack A. Duncan – VCU – School of Education.

Active Listening:

People who have faced difficult experiences or struggled with difficult emotions say that the most helpful thing anyone can do for them is to listen – not try to provide solutions to their problems.

Active listening means trying to understand exactly what another person is saying and letting that person know that you have understood. When you are actively listening, you are paying attention to both what is being said and the feelings expressed by that person.

Techniques for being an active listener

- **Be Attentive:** Pay close attention to what is being said.
- **Be Impartial:** It means not agreeing, disagreeing or even sharing any opinion you may have. Remember, the purpose of active listening is to understand the other person.
- **Reflect Back:** Use similar words to repeat the speaker's statements back to him/her.
- **Listen for Feelings:** Often the feelings that the speaker shares are the most important part of their message. Listen carefully for those feelings and acknowledge them. You can say... "You seem angry" or "You seem to have some concerns about" or "You sound frustrated."
- **Summarize:** Pick out what you think are the most important parts of the speaker's message. Repeat these back to be sure you understand and to let the speaker know that you understood.

Active Listening section adapted from Family-Centered Communications Skills Facilitator's Guide, 1992.

Roadblocks to Communication

- Ordering, Directing: "You must do this," or "Stop it."
- Warning: "You had better do this, or else," or "I warn you, if you do that..."
- Ought, Should: "You ought to go to the hospital," or "It is your responsibility to do this."
- Advising: "What I think you should do is..."
- Lecturing: "Here is the right way."
- Judging, Criticizing: "You are acting foolishly," or "You are wrong."
- Praising, Buttering Up: "You have so much potential."
- Name Calling, Ridiculing: "You are a sloppy worker."
- Diagnosing: "You are being paranoid," or "You are jealous."
- Reassuring, Consoling: "It's not that bad," or "Things will get better."
- Interrogating: "Why did you do that?"
- Distracting: "You think you have problems."

Adapted from Leader Effectiveness Training, by Dr. Thomas Gordon, 1980.

Questions

Generally, questioning is used to elicit information you want or to elicit information from the person he/she may need to consider. The best questions for eliciting information and feelings from another person are open questions:

Open Question: is one that allows/encourages the person to provide more than a simple "yes," "no," or "I don't know" kind of response. For example:

- What kinds of things generally happen when you have a seizure? (Exploratory question)
- When do you find that you have the most symptoms? (Cognitive question)
- I'm wondering how you feel when you experience those symptoms. (Indirect question)
- You say you've tried everything you can think of to feel better about your situation, but nothing seems to work. (Indirect question)
- Just the very thought of having surgery to control your seizures and not getting the results you anticipated is upsetting. (Interpretive question)
- I'm not certain I know what you mean when you say your parents are responsible for your difficulty limiting stress in your life. (Clarification question)

There are other types of question with which you should be familiar. These are used in casual conversation, but should be used sparingly, if at all by peer partners. These types of questions include closed questions, multiple questions, and why questions.

Closed Question (can close down conversation, so should be used sparingly): is one that allows/encourages the person to respond with a simple “yes,” “no,” or “I don’t know” kind of response. For example:

- Do you have seizures often?
- Did you feel sorry after you screamed at your kids when you weren’t feeling right?
- How many times did you have a seizure last month?
- Who is the one person who most often raises your stress level?

Multiple Question (can be misleading): is one question embedded within a single presentation.

This kind of question tends to confuse and mislead the person. For example:

- Will you be continuing your therapy to control your stress or have you not discussed this with your husband?
- Do you think that most of your problems stem from your numbness or when do you expect to find an answer to your problems?

Why Question (can be misconstrued): is one that focuses on the reasons or motivations behind an individual’s thoughts and/or actions. Although there are times that the why questions may be used, the following is a list of possible results of using this kind of question:

- Tends to establish a superior-inferior relationship
- Tends to place the person on the defensive
- Tends to be confrontive
- Tends to imply that the person must justify his/her thoughts or actions
- Tends to ignore the person’s feelings
- Tends to inhibit or cut off communications
- Tends to yield less than insightful responses

A why question that is directed toward a situation, an event, a procedure, or a policy that does NOT reflect direct responsibility on the person to whom the question is asked is usually non-threatening.

Non threatening example: “Why does the physical therapy center you attend require a month’s payment in advance?”

A why question that is directed toward an individual who may have some responsibility in the situation may be very threatening:

Threatening example: “Why do you feel you should not have to pay a month’s payment in advance to the physical therapy center you attend?”

Inappropriate Use of Questions: Questions are inappropriately used when they:

- Create a dependency relationship
- Create a defensive posture in a person
- Inhibit open responses by the person
- Encourage the person to provide inaccurate information
- Create inattentiveness in the person asking the question
- Develop a false sense of security in the person
- Create indifference in the person

Communication “Leads”

To understand another person’s feelings and experiences we need to attempt to enter their personal frame of reference through which they interact with their world. However, since it is impossible for us to be the other person, the best that we can do is strive for reasonably correct but approximate understandings. With this in mind, it seems desirable that we be continuously open-minded and cautious in appraising others, consider most judgments as tentative, and remember that, at best, we will have a limited understanding of the unique person with whom we are interacting.

Phrases that are useful, when you trust that your perceptions are accurate and the helpee is receptive to your communications:

- You Feel ...
- From your point of view ...
- It seems to you ...
- In your experience ...
- From where you stand ...
- As you see it ...
- You think ...
- You believe ...
- What I hear you saying ...
- You’re ... (identify the feeling, for example, angry, sad, overjoyed)
- I really hear you saying that ...
- Where you’re coming from ...
- You figure ...
- You mean ...

Phrases that are useful when you are having some difficulty perceiving clearly, or it seems that the helpee might not be receptive to your communications:

- I’m not sure if I’m with you, but ...
- Would you buy this idea ...
- What I guess I’m hearing is ...
- Correct me if I’m wrong, but ...
- Is it possible that ...
- Does it sound reasonable that you ...
- From where I stand, you ...
- This is what I think I hear you saying ...
- You appear to be feeling ...
- It appears you ...
- Perhaps you’re feeling ...
- I somehow sense that maybe you feel ...
- Is there any chance that you ...
- Maybe you feel ...
- Is it conceivable that ...
- Maybe this is a long shot, but ...
- Maybe I’m out to lunch, but ...
- Do you feel a little ...
- I’m not sure if I’m with you; do you mean ...
- I’m not certain I understand; you’re feeling ...
- As I hear it, you ...
- It seems that you ...
- ... is that the way it is?
- ... is that what you mean?
- ... is that the way you feel?
- Let me see if I understand; you ...
- Let me see if I’m with you; you ...
- I get the impression that ...
- I guess that you’re ...

Taken from Gazda, et al., Human Relations Development, a Manual for Educators. 2nd ed., Boston, Massachusetts: Allyn and Bacon, Inc., 1977.

Adapted from Parent to Parent – February 1995 – Greater Richmond Metro Area. Jack A. Duncan – VCU – School of Education.

Conflict Management

Causes of Disputes

- Differences in values, philosophy, goals, or objectives
- Differences of opinion
- Differences in perception
- Role pressures
- Simple misunderstandings
- Poor communication
- Inaccurate or insufficient communication
- Limited resources
- Fights for power, turf, or control

How to Resolve Conflicts

A peer partner may become angry when they do not feel their needs are being met or that you are not sensitive to their needs. Recognize and accept their feelings. Take time to discuss their concerns. Seek help from the Peer Support coordinator. Never threaten to terminate your partnership because they complain.

If you disagree: 1) focus on the individual's best interest; 2) emphasize what's right rather than who's right; and 3) begin with areas of agreement and work from there. When your views of "reality" differ, explore both views to understand each other's concerns.

Separate the people from the problem. People problems frequently fall into three basic categories: perception, emotion, and communication. If perceptions are inaccurate, look for ways to educate. If emotions run high, find ways for each of you to let off steam. If there are misunderstandings, work to improve communication. You must also learn to deal with your own problems. Don't let anger and frustration affect your peer relationship.

Perceptions:

How you see the world depends on where you sit. People see what they want to see. The ability to see situations from another point-of-view can help you solve problems. Understanding the other person's point-of-view is not the same as agreeing with it.

One way to deal with differing perceptions is to discuss them openly, without blaming anyone.

Emotions:

Recognize and understand personal and family emotions, as well as yours. Why are you angry? Why are they angry? Are they responding to past grievances?

Talk about your peer partner's emotions. A good way to deal with anger or frustration is to help individuals release their feelings by airing their grievances. Listen quietly without responding to attacks. Many times an apology can diffuse emotions effectively even when you do not acknowledge personal responsibility for the problem.

Communication:

Communication is important in resolving problems. There are three basic communication problems:

1) You may not be talking to each other; 2) You may not be hearing each other; and 3) You may misunderstand each other.

What can be done about these communication problems?

- Be a good listener. Pay close attention to what is said and ask the person to spell out exactly what they mean.
- Make sure the other person understands you.
- Speak for yourself, not for the other person. Tell how the problem affects you.
- Be knowledgeable, but don't pretend to know everything.

Preventing People Problems:

The best way to handle people problems is by not allowing them to develop. Build a relationship with your peer partner. Get to know them personally.

Section III

Taking Care of Yourself as a Peer Partner

“I was just getting comfortable and dozing off, trying to ignore the all-too-familiar pre-flight instructions from the flight attendant as we taxied to the end of the runway. But I found myself listening anyway. What struck me was the part about donning our own oxygen masks before assisting anyone else in putting on theirs. It made total sense, of course. While you selflessly help another, you could easily pass out from lack of oxygen and be of no help to anyone.”

It's something I've learned before, but seem to have to relearn over and over in different circumstances; to help others, you have to take care of yourself. I originally recognized this in my family. I often put everyone else first and didn't take care of my own needs. I falsely believed that if I did something for myself I was taking something away from others. In fact, what happened was that I had less of me to give.

What are some ways that you can take better care of yourself? Taking time for yourself. This is so very important. You need the time for revitalizing the spirit. Don't neglect this. Here are some key methods:

- Incorporate activities that give you pleasure even when you don't really feel like it. Listen to music, work in the garden, engage in a hobby...whatever it is that you enjoy.
- Pamper yourself. Take a warm bath and light candles. Find some time for a manicure or a massage.
- Eat balanced meals to nurture your body. Find time to exercise even if it's a short walk everyday. Do the best you can to sleep at least 7 hours a night.
- "Laughter is the best medicine"...buy a light-hearted book or rent a comedy video. Whenever you can, try to find some humor in everyday situations.
- Keep a journal. Write down your thoughts and feelings. This helps provide perspective on your situation and serves as an important release for your emotions.
- Make time for friends and family who nurture you and lift your spirits.
- Exercise. This is one of the easiest things to let slide, either because we don't feel that we have the time or that we just aren't worth it. You will actually have more time, or at least more productive time, if you see this activity as a must-do.
- Draw strength from your faith.

Only you know what special treatment is best for you, but the ideas mentioned above should get you started. Our society doesn't give much recognition for being self-indulgent, but being there for others requires that we take excellent care of ourselves.

An excerpt from “Taking Care of Yourself” by Michael Angier and also from http://www.helpguide.org/elder/caring_for_caregivers.htm

Additional suggestions for taking care of yourself

Make Time for Playtime

That old saying about all work and no play makes Jack/Jill a dull boy/girl still makes sense. Also, all work can give Jack an ulcer or harm his health in some other ways. If Jill has trouble taking it easy long enough to get some fun out of life, she probably ought to schedule time for recreation.

Loaf a Little

Very active people may feel guilty about occasionally sitting and doing nothing much. We need to learn the art of loafing. While too much inactivity may actually cause stress, a few minutes a day doing nothing may help us tackle our work with renewed enthusiasm.

Put Off Things

Procrastination with a purpose can be a good thing. Learn to let some things go. Remember that we can only do one thing at a time. Concentrate on the particular job at hand and then go on to the next job, without worrying about everything that has to be done. Some things can be set aside until later, even until tomorrow.

Work Off Tensions

When upset or angry, we can try to blow off steam or work off our feelings with physical activity. Walking, housework, gardening, or sports not only help to relieve tensions, they make it easier to face problems more calmly.

Talk Out Troubles

Confiding our worries to a sympathetic ear helps get it off our chests. Another person may help us get our feelings into focus and to see our problems in a new light.

Learn to Accept

There are circumstances beyond our control and things we cannot change. Sometimes we must learn to accept the situation and move on, and move forward. For example, we may try to make people over to suit our own ideals. That doesn't work. Instead, we can look for the best in others while still realizing that nobody is flawless.

Get Away from It All

We can divert or distract ourselves when we feel that we need a break from routine or that we are going around in circles with a worry. Going to a movie, reading a book, or visiting a friend are simple ways to help us out of a rut. When possible or practical, a change of scene can give us a new perspective. There's no harm with taking a break from a difficulty long enough to regain the strength we need to come back to the situation.

Have Regular Check-ups

It's important to go to our doctors for periodic check-ups. Just as the mind affects the body's working order, physical condition affects outlook on life. If we keep ourselves as fit as possible, we'll have more zest for life.

Everything in Moderation, Everything in Balance

Of course there are no easy or simple solutions to the day-to-day hassles and difficulties of life. Personal experience and learning from others will help us handle stress with more grace and live life with more purpose. We can encourage each other to do things in moderation and keep things in balance – work, play, and rest.

Adapted from the Kidney foundation of Canada's Peer Support Guide, 2003.

Quick Reference Guide

Do's and Don'ts

Do's:

- listen and give feedback when asked
- write down what the person says
- answer questions
- ask them what is on their mind
- ask them to clarify any specific problem
- allow emotions (including crying)
- speak softer as they speak louder
- respect their need for privacy
- go slowly
- check back with them if they don't call
- respect lifestyle if different from yours

Don'ts

- argue
- defend or become defensive
- promise things you can't produce
- probe for information not given
- interject while the person is speaking
- raise your voice
- belittle or minimize their problem
- make moral judgments
- give advice
- be afraid of silence
- push acceptance

Some Helpful Things to Say

- It's okay to feel sad. You have a right to feel that way.
- You are not alone. I will be here for you.
- What can I do to help sort out the situation?
- There are some resources that might be able to help you.
- I don't have all the answers, but maybe I can make a few suggestions.
- Above all, remember you know yourself (or your child) the best.
- Love and enjoy yourself, and your family.

Phrases that are useful, when you trust that your perceptions are accurate and the helpee is receptive to you communications:

- | | | |
|-------------------------------|---|-------------------------------------|
| • You feel ... | • You think ... | • I really hear you saying that ... |
| • From your point of view ... | • You believe ... | • Where you're coming from ... |
| • It seems to you ... | • What I hear you saying ... | • You figure ... |
| • In your experience ... | • You're ... (identify the feeling,
for example: angry, sad,
overjoyed) | • You mean ... |
| • From where you stand ... | | |
| • As you see it ... | | |

Phrases that are useful when you are having some difficulty perceiving clearly, or it seems that the helpee might not be receptive to your communications:

- | | |
|--|--|
| • I'm not sure if I'm with you, but ... | • Is it conceivable that ... |
| • Would you buy this idea ... | • Maybe this is a long shot, but ... |
| • What I guess I'm hearing is ... | • Maybe I'm out to lunch, but ... |
| • Correct me if I'm wrong, but ... | • Do you feel a little ... |
| • Is it possible that ... | • I'm not sure if I'm with you; do you mean ... |
| • Does it sound reasonable that you ... | • I'm not certain I understand; you're feeling ... |
| • Could this be what's going on, you ... | • As I hear it, you ... |
| • From where I stand, you ... | • It seems that you ... |
| • This is what I think I hear you saying ... | • ... is that the way it is? |
| • You appear to be feeling ... | • ... is that what you mean? |
| • It appears you ... | • ... is that the way you feel? |
| • Perhaps you're feeling ... | • Let me see if I understand; you ... |
| • I somehow sense that maybe you feel ... | • Let me see if I'm with you; you ... |
| • Is there any chance that you ... | • I get the impression that ... |
| • Maybe you feel ... | • I guess that you're... |

Email Starters

Greeting:

Hi _____

My name is _____, and I'm a member of the Angioma Alliance. I look forward to supporting you as much as possible through this difficult and confusing time. While I do not have all of the answers, I can help you learn the right questions to ask. I should probably tell you a little bit about myself. (briefly describe your symptoms, diagnosis, and other pertinent information relating to your experience with angiomas or your loved ones' experience).

I would love to hear from you and learn about your experience so far and what you're going through. I know from personal experience that living with angiomas can be very physically and emotionally draining. . Anything you wish to share about your symptoms, emotions, frustrations, etc., would be helpful. If you're not yet ready to go into great detail, that is fine too. Whenever you are ready, I'll be here to help as much as I can.

I usually check my email (time of day) and I hope to hear from you soon!

Best wishes,

Checking in:

Hi _____

I haven't heard from you in a while but I wanted to let you know that I'm thinking of you. If you need to, feel free to contact me. If you're doing well and keeping busy, that's great too. I just wanted to let you know that I'm here if you need me.

Best wishes,

Termination:

Hi _____

I wanted to let you know that recently there has been a big change in (my personal life, my career, etc.). Unfortunately, that means that I will no longer be able to be your official support person.

OPTIONAL: While I'm resigning my official capacity as your Angioma Alliance support person, I will be happy to continue an informal email dialog with you as time permits.

Fortunately, _(name of new support person)_____ should be contacting you shortly to pick up where I left off.

I truly enjoyed talking with you and sincerely wish you the best!

Replacement Support Person Introduction:

Hi _____

Although (name of previous support person) has new commitments and can't continue providing support, I'm pleased to "take the reigns" and continue providing support to you as you wish. (Name of previous supporter) forwarded enough information about you so that I have a good understanding of the issues with which you are dealing.

You and I have a number of similarities! (briefly describe your symptoms, diagnosis, and other pertinent information relating to your experience with angiomas or your loved ones' experience).

If there have been any new developments, which I may be un-aware of, please feel free to fill me in. I very much look forward to helping you as much as I can.

Kind regards,