Patient Rheumatoid Arthritis Social Support Initiative

BRIGHAM AND WOMEN'S HOSPITAL

Rheumatology Division – Arthritis Center

Peer Support Training Materials

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PARASS Peer Support Training Materials

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www.PARASSstudy.org

Table of Contents

CHAPTER 1- COMMONLY DISCUSSED TOPICS

CHAPTER 2- ROLE PLAYING EXERCISES

CHAPTER 3- VISUALIZATION AND RELAXATION EXERCISES

CHAPTER 4 – STRUCTURE AND IDEAS FOR MANAGING THE PHONE CALL

CHAPTER 5- MAKING THE FIRST CALL

Chapter 1

Peer Coach Training:

Key Purpose of a Peer Coach

To provide a sense of hope and let a patient know there is someone they can talk to. Not everyone will have the same circumstances because there are various kinds of arthritis and different ways it develops. If your participant can glean from you that you are living a life that you like this will go a long way. They will also understand that you approach life with enthusiasm. Yes, it isn't always clear-cut but there are a lot of good people out there you can count on. Even if your resources at home aren't great there are often people that are helpful. It is difficult at first when you are told you have something wrong with you. If you can accept and deal with it, then you will go a lot further. Approach it as, "I am dealing with this now, I will deal with it with a certain amount of enthusiasm to get through it and that is how I will endure it." Maybe it is your faith in God or your knowing that you have a future and have obligations, or you may have children to raise that helps you get through it. There is another side. It will be good again. (Fran Griffin, BWH Arthritis Clinic Nurse)

**"Sometimes all the person wants is to have someone listen to them."
Speak from your experience.**

Mental health

Being diagnosed is frequently experienced as a loss. A person mourns for what they did before, often going through the stages of grief - denial, anger, and sadness before coming to acceptance. It is unpredictable how a person will feel from one day to the next. Over time individuals come to understand that they are a person with RA rather than an RA patient, or a person being consumed by the disease. "You are still the same person. Just your life has been changed."

1. **What if someone unburdens about family problems or other personal issues?**

Some RA patients would just like to talk and have someone listen. Others might really need counseling if their personal problems are more difficult. If the person expresses problems beyond their disease, e.g., a spouse who turns away, problems dealing with family members, concerns about life history or childhood, refer them to their doctor. These concerns are more for a counselor rather than a peer coach.

2. **What if my participant is anxious and angry?**

When someone expresses anger, don't take it personally. You can say, "I understand. It makes sense that you feel upset." Anger and other emotional reactions are not unusual for someone dealing with a chronic disease. Having RA is a journey. Peer Coaches can share how they reacted when they were first told they had RA.

People get angry, afraid, and frustrated. There are things you are no longer able to do, e.g., turn door handles, turn ignition in the car, cutting vegetables. Share some of the things you have done to make it easier, e.g., have someone come in to clean the house instead of doing it yourself, asking others to help, a neighbor to help pick up or rake leaves in your yard.

3. **How would you guide someone who is under a lot of stress?**

Maybe ask them, "What is making you so stressed? Could you try something different?" Could you prioritize what you have to do? Leave the bed unmade, or order take- out food, and rest between tasks. You can sympathize with how hard it is not to do what you are used to doing. One patient liked to bake, but stopped because she would get too tired. Then, she figured out to stop in between baking steps and rest.

Stress: is a cue to slow down. Dealing with RA requires a balance. On one hand you need to push yourself, but not to a point that is destructive, or causes you to crash. It is hard to lose your independence. You can push yourself, but you also have to depend on others.

4. **What if your participant cries?**

Sometimes the patient may cry. It is good to allow the person to cry and, in fact, it is a sign that the patient trusts you enough to express this emotion. You could respond, "I understand it's very hard having a chronic illness. I felt the same way."

Doctor patient relationship

1. **How can you help someone communicate better with his or her doctor?**

You may not be able to change the way a person interacts with their doctor. Sometimes it takes time for the patient to build a trusting relationship with their physician. If they are timid, they may not be able to ask all their questions. To help with communication, a person can bring a list of questions to their visit, remembering to write down the most important one first, in case you cannot ask them all during the visit.

If the person is not very assertive, a peer coach can work on ways to help, e.g., suggest that the person bring a support person with them to the visit.

People have different approaches to their doctor. Some people would like their doctor to tell them what to do, while others want to have more information, and more say in what happens.

2. **What if a person complains about their doctor?**

You can suggest that they talk with their doctor directly. If you find that they are uncomfortable talking with their doctor, you might say that it is important for you to be comfortable with your doctor and maybe your current doctor isn't a good match." You might suggest that they consider switching. If so, you could suggest that they give Pat Green or Fran Griffin a call to see what doctors are available and whom they might recommend."

Medical

1. **How long before people get diagnosed from the start of their symptoms?**

About 6 months. If you get aggressive treatment, you can begin to feel better once the medication has taken effect. While the new medications do prevent deformity, this doesn't mean you don't feel lousy. Keep in mind, 20% of people do not respond to the biologics.

2. **What can we say if someone asks about medications?**

   Please don't give medical advice. It is fine to share you experience, but emphasize that each person is different. Refer them to their doctor for specifics. When it gets into advising patients about changing medications they should be referred back to the doctor or the nurse. Your greatest tools are your instincts and your experience.

3. **Is it ok to give suggestions?**

   Sure, it is fine to share tips that work for you, such as, "When I am tired, this is what I do." Or "To help myself get out of bed, I do…" Suggestions that help a person live better with RA are most helpful. Focus on the here and now.

   The Arthritis Foundation has great brochures including some on medications, exercise, and nutrition. Anything you say from those brochures is ok because they have been screened and edited.

Medical questions you might be asked

1. **How long did it take to have the medicine work?**

2. **Did you have immediate relief or did you have to add or change your medication?**

   Example Responses: Drugs work differently with different people.

   "I went through a period where I tried different medications until I found the one that worked for me. Sometimes it takes several kinds of medicine before you begin to feel better." Or, "I started on a new medication and, at first, it did well, and then, a few months later, it didn't. So, for me, it took months before anything worked. But, I did find something, and now live an active life." New medications are being developed and tested all the time.

   Even if your experience was negative, you can end on a hopeful note. (ie. there are a lot of different medications and they are finding new ones all the time) Currently, there are 18 biologics under research.

3. **Are there any alternative therapies and treatments that you can do with RA?**

   Yes, there are resources at the Brigham and Women's Osher Center for acupuncture, massage, nutrition and more.

   The research isn't clear about the benefits of particular herbs, and some interact negatively with RA medications. It is best for the person to check with their doctor if there is any question whatsoever. You can read an overview about "Herbs, Acupuncture, Massage and Exercise on the Brigham and Women's BRASS website.
   http://www.brassstudy.org/?page_id=65

4. **What medications are you on and what were you on?**

   Example response:
   It is fine to talk about what you were on and what you are currently taking, but emphasize that there isn't one right medication. Your doctor will work with you to find the right medication and dose. **"**I started on ____ medication and now I am on _____ medication.

Living with RA

1. **How do you help someone who is in a lot of pain?**

   There is the pain cycle. You can suggest meditation, relaxation, and hot and cold compresses. The Arthritis Foundation has a pamphlet on how to cope with pain. You can find information about managing your pain on the Arthritis Foundation website at http://www.arthritis.org/understanding-pain.php

2. **What do you say to someone who is young and thinking about getting pregnant?**

   Share your own experience, but refer the patient to their doctor because the doctor can discuss the options, and the doctor needs to know that this is something the patient is considering.

3. **Can you make suggestions about what you do for exercise?**

   Best not to specify any particular exercise, but it is fine to talk about what works for you. For example, "I used to do pool therapy. I enjoy it. There is no resistance on your joints. But talk with your doctor to find out what exercise is best for you."

4. **How long have you had RA yourself? Were you afraid or angry when you were first diagnosed?**

   Were there many things you were not able to do such as opening jars? Turning the key in the ignition of your car?

5. **How did your spouse and/or your family responded to your having RA?**

   Some people have had family members become closer and for others the opposite happened. It can happen that friends or family members have a hard time dealing with your diagnosis and act in ways that are not supportive and in some cases, may walk away. These are not relationships that we would want at this point. Better to have people around you that are supportive.

6. **"I am so sad. I used to be able to dance."**

   With the new medications you could go back to dancing sometime in the future.

7. **What did I do to cause this?**

   People take having Ra personally. Reassure them that they did nothing to cause it. No one knows what causes RA.

8. **"When am I going to be pain free, or get back to my normal life?**

   It differs for everyone. Some of the medications work quickly, while others can take a few months to really have an effect. It also depends on your disease and how your body reacts. For some it can take longer.

9. **How good should I expect to feel? Am I ever going to wake up and feel like I don't have RA?**

   A response to this question should help patients set goals for themselves. You can suggest, "Try to make it so you wake up and not feel set back. This doesn't mean you don't have RA, but you are moving forward. With all the new medications available, people live very active and productive lives. It is no longer like the old days when people would end up in a wheel chair.

10. Will I be ok? Will I have a future? Will I be able to have a family?

Share your experience of when you were first diagnosed and where you are today. When you are first diagnosed, everything looks bleak and you cannot envision living without pain or having a productive life. Your experiences will be reassuring that a person with RA can live a full and productive life.

Chapter 2

Role Playing Exercises

- **Role Playing Process:**

  a) People move their chairs to form a circle.
  b) The training facilitators sit in the center and act out the role play.
  c) Afterwards the group discusses other possible ways to handle the situation.

- **In thinking about conversing with your participant**:

  a) Remember that you have been through the experience and have a natural sense of what is important
  b) Think about your own style and what you might be comfortable saying.
  c) The environment you want to create is for the participant to be able to express what is going on. You as peer coach can offer a perspective that it can get better.
  d) You can also offer your experience of what happens.

1. **Role playing – when your participant expresses a problem or is feeling anxious or depressed. Example "**A patient says that s/he is concerned that s/he cannot keep up relationships with friends and is uncomfortable in telling them that s/he is too tired to go out."

   If you are talking to a participant that is having problems, this may bring up multiple reactions in yourself. If you notice your immediate reaction, also notice that it is not the only response you are capable of inside. This noticing helps you stay in a positive empathic place.

Notes:

Points that you thought were helpful

Aspects you might use with your participant?

2. **Role play – opening the conversation with your participant/partner.**

   How do you find out what is the particular concern for your match? (Possibilities – Ask why the participant wanted to have a peer coach. What do they hope to get out of it.)

   Helpful rules

   - Tell the person early in the phone call front how much time you can talk.

Notes:

Points that you thought were helpful

Aspects you might use with your participant?

3. **Role play – ending the phone call with your participant/partner.**

   Ending the phone call can be difficult. What are possible ways to make it easier for both you and the participant?

Helpful rules

About 10 minutes before the end of the phone call, you might say, *"Looks like we have 10 minutes left, what is the most important thing for us to focus on for that bit of time."*

Notes:

Points that you thought were helpful

Aspects you might use with your participant?

Chapter 3

Visualization and Relaxation Exercises

[Note: From the benefits – we can plant some seeds – learning some self-management skills for yourself. Moving from that we can go into one of the visualizations or relaxations]

- **Visualizations -** visualizations for inner calm in an anxious environment or with anxious people

  a. River meditation – person visualizes themselves resting by a river in a comfortable position. Little hypnotic for relaxation, you notice the air, the feel of the sun on your skin. You look at the river and notice the calm of the water, notice that something is in the river that is coming closer. You watch it as it floats by. The things that come down the river, there is nothing you have to do, just watch it as it comes closer, and closer, curiosity and just watch it go down stream.
  Adapt it for a group – object flowing downstream that for you represents a heightened form of anxiety …as it gets closer your anxiety rises but as it flows by the anxiety goes with you.

  b. Mountain meditation – everybody is sitting in a chair. Everyone imagines a mountain - one you know or from imagination. Example Details – the firm base, center of the mountain is big, solid, and image the peak. You imagine becoming a mountain, your bottom is the base of the mountain, your torso as it rises up, and your head is the peak. It gets buffeted by seasons – winds, cold, but all the while the mountain just sits. You notice that as you feel the mountain in your body, notice how it feels, how you feel in your body, your head, notice that strength no matter what is going on in your body. As you leave this training, this strength stays with you, your core has helped you through your life, and this stays with you.

- **Relaxation techniques when in the midst of stress**

How help when in the midst

a. <u>A relaxation cue</u> – as you are in this relaxation state, notice your body, notice there may be a particular visual cue that can help you stay relaxed, something you can evoke no matter what is going on. It may be having your spine upright, it maybe the visualization of that mountain rising from your bottom rising up to your head. Every time you have a stress situation, you will remember this visualization. Practice in your home. Can be done in 20 minutes.

b. <u>diaphragmatic breathing</u> – as this person is in pain you can keep breathing and holding your strength and sending it to them.

c. <u>if someone is anxious</u> – you breathing in murky color and filtering it through your heart center and giving it back to them.

What did you find was helpful? How do you think it might be used working with your participant?

Chapter 4

Structure and Ideas for Managing the Phone Call

Initiating the phone call

- Phone call duration - 20 to 30 minutes
- Scheduling – include the length of time
- Make a plan about when to talk the next time before ending the first call.
- Peer Coaches will call the participant.
- What if the person doesn't answer when you have scheduled the call? You can leave a message if you are calling as scheduled. Please call me back, if you are late or if something has come up, so that we can schedule the next time.
- When you hear back reschedule the call for a time later that week if you are so inclined or schedule it for the following week.
- If you don't hear back you go about your day. Try again when you have time. If you still don't hear from your participant in a day or two, please contact xxxxx so that we are aware that this has happened.

During the phone call

- If something comes up and you have a concern or a questions, don't hesitate to call one of the PARASS team. (Team members and phone numbers below). If you think that the person is depressed, please contact xxxxx and if you don't reach xxxxxx, call xxxxxx
- Please jot down some notes about what is discussed during the phone call. What is your sense of how your partner is doing, what topics come up, anything of note that you think is important.

- Remember that even if you cannot solve their problems, that having a caring person listening and connecting will make a big difference for your participant.

Closing the phone call – some things you can say

- We have ___ amount of time left, I want to make sure that if there is anything real important to say or talk about that we talk about it now. (The door knob phenomena, e.g., sometimes people wait until the end of a meeting to bring up the most important topic)
- Any last thoughts before we go?
- So what is happening for you after we hang up? Pick up on what it is, and then to close the conversation pick up on what they are going to do next and wish them well and talk next week.
- If there is still a lot to talk about, tell the person, "let's pick up on this the next time we talk." If you feel the person needs more time and really needs to talk, please call us and we will set up a referral.
- If the person still continues talking, you could say, "I noticed that we have run out of time. We will continue talking about this during our next phone call.

Reminders:

You are modeling self care by putting boundaries on the call. If you are newly diagnosed and you are getting used to living with limitations that you didn't have before, and need a model of how to do that with self-respect. By limiting the amount of time, you are helping them develop that sense.

Your role is as a partner in care, providing information, helping your participant find ways to manage their disease, offering advice, support and encouragement. If you are comfortable, let the person being coached control the agenda of the phone call.

Chapter

5

Making the First Call

If you call and reach your partner, please skip to the section of "the first conversation."

If you do not reach your partner and you can leave a message, please include the following in your message.

- **Why you called** – "I am a RA patient at the BWH and part of the Patient-to-Patient Connection program. I was given your number as someone who might be interested in talking to another RA patient."
- **Leave your phone number and good times to reach you**.
- **Include that you will try them again too.**
- **If you use email, you might suggest using email for communication.** For example, "When we connect, we can decide how we will communicate – some people prefer by phone, others by email. "

The first conversation:

- Introduce yourself as someone who has RA and is interested connecting with others.

- Some people may need to be drawn out. Questions to start with can include:

    1. How did you hear about the Patient-to-Patient Connection Program?

    2. How interested were you when you found out about it?

    3. What do you know about the program? Points to include are:

        a) This was designed by patients because so many RA patients haven't had the opportunity to talk with another RA patient more than superficially.
        b) Talking with another RA patient, we find out how many experiences we have in common and that we are not the only one.
        c) Some people are interested in just having a person to call occasionally. Others would like to talk once or twice to hear another patient's experience on a particular issue or topic. Others might like to have another patient to talk to over a period of time.
        d) This program can be used just to connect you to resources that are available at the hospital.
        e) Some people have used this program to find ways to improve their visit with their rheumatologist.
        f) Some people want to talk about a particular issue, which can range from something related to mobility, to exercise and nutrition, or to more personal concerns,
        g) Importantly, we can work out ways this program would be most useful to you.
        h) "Some people want more and some people want less. Some people want to talk a couple of times and then decide after they have seen how it goes. "
        i) What are you thinking would be best for you?"

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