

PEER COACHING FOR KIDNEY PATIENTS



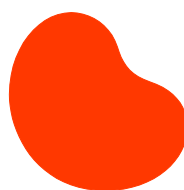
MANUAL FOR PATIENT COACHES

ACKNOWLEDGEMENT

The Renal Network of the Upper Midwest, Inc. (Network 11) developed this resource.

Network 11 thanks the National Kidney Foundation of Michigan for use of its copyrighted Peer Mentor Program and Training materials in the development of our Peer Mentor Program.

*A special thank you to the Network 11 Consumer Committee
for all of their hard work on this project*



National
Kidney
Foundation® | of
Michigan

FORWARD

Almost twenty years ago, my unit's social worker recommended me as a candidate to receive the National Kidney Foundation of Michigan's (NKFM) Peer Resource Consultant Training. I can honestly say that it proved to be a life changing experience for me. Being able to help others achieve some level of acceptance with their own diagnosis of End Stage Renal Disease (ESRD) and move forward to a richer, happier life is incredibly fulfilling. I can honestly say that the training itself was one of the most powerful experiences of my life.

The NKFM program training was life changing for me in every aspect. The principles of active listening, diffusing anger, and recognizing and identifying feelings have helped me immensely both professionally and personally. For me, the most valuable lesson was setting aside my own value system and identifying the values of those around me. This simple lesson has broadened my ability to work with all kinds of people tenfold.

In my experience, the NKFM Program (now called the Peer Mentor Program) is the best training I have seen of its kind. The program handouts I received 20 years ago are still in my possession and are part of my everyday life. The peer mentoring concepts are logical and effective. Many of the same concepts I learned then, are being presented here in the same effective format.

Thank you, NKFM, for helping to shape my life. Who would have thought that my own kidney failure would prove to be such a blessing in disguise?

Maggie Carey

Network 11 Consumers Committee Chair

CONTENTS

| | |
|---|-----------|
| Acknowledgement | i |
| Forward | ii |
| How to Use this Manual | 1 |
| Introduction | 1 |
| Purpose and Objectives | 2 |
| What is a Coach?..... | 3 |
| 10 Coaching Guidelines..... | 6 |
| Peer Mentoring Best Practices | 7 |
| Preparing to Be a Coach | 8 |
| Self-Reflection | 9 |
| Relating to Others | 9 |
| Setting Your Priorities | 12 |
| Assessing Your Assertiveness..... | 16 |
| Knowing Your Limits | 24 |
| What All Coaches Need to Know | 25 |
| Confidentiality..... | 25 |
| Communication Skills..... | 27 |
| Values, beliefs, feelings..... | 35 |
| Helpful Resources | 48 |
| Grief and Loss..... | 48 |
| Sexuality, Body Image, and Chronic Kidney Disease | 60 |
| End of Life Decisions | 68 |
| Serving as a Coach | 71 |
| Arranging Appointments..... | 71 |
| Establishing Relationships..... | 72 |
| Discontinuing Relationships..... | 73 |
| Additional Resources | 74 |
| References | 75 |

HOW TO USE THIS MANUAL

INTRODUCTION

Welcome to your first steps on a magnificent adventure. You have chosen to look over this material because you are an incredible person with a gift that you are considering sharing with others. You have made a good transition to life with End Stage Renal Disease, and your social worker and unit staff recognize all that you have accomplished. Now you are willing to help others make their own transition.

If you choose to continue with the program, you will find great personal reward. However, we are the first to admit that the road will not always be smooth. As you work with new patients in your unit, or other referrals that you receive, you will be reminded of all your own fears and concerns while you were adjusting to your new life with ESRD. You will undoubtedly be asked questions on topics that you may not feel comfortable with.

Rest assured that we are here to help, support and encourage you in all aspects of this important work. The first step is for you to thoroughly read and study this Coaching Manual. It is organized by topic to help you develop the skills you need to successfully coach others. In addition, it will prove to be a handy reference tool when questions and concerns arise.



PURPOSE AND OBJECTIVES

At the request of physicians, social workers and/or other team members, coaches provide support to people with ESRD and/or family members. The emphasis of this coaching program is to help new patients and their families adjust to life with ESRD.

OBJECTIVES

1. Be a role model
 - a. Involvement in one's own health care
 - b. Opening up difficult issues and help to problem solve
2. Provide Information
 - c. Sharing with people who are new to the unit or changing modalities
 - d. Sharing special resources from your local Network or other organizations
 - e. Sharing one's own experience, yet balancing that with others' experiences and the unpredictability of all treatments
3. Act as an empathetic listener (not giving advice)
4. Teach strategies for working within the health care system
 - f. Learning to make a list of questions
 - g. Communicating openly for better diagnosis and treatment by the health care team
5. Relieve anxiety: The coach's presence conveys the message to new patients that "if he or she can make it, I can too."
6. Legitimize Patient and Family Feelings: Sharing one's own problem areas allows others to do the same more easily and then to communicate these areas to the team
7. Develop a culture of Patient Centered Care
 - h. Taking responsibility for one's own health care
 - i. Creating and taking an active stance in this unpredictable arena of life and death
8. Encourage patient advocacy – teaching patients to advocate for themselves

WHAT IS A COACH?

Coaches are individuals who have made a positive adjustment to their own End Stage Renal Disease. They are willing and available to support others who are currently trying to adjust. Coaches are an extension of their dialysis unit's health care team and work under the direction of the unit's Social Worker.

Coaches are not advice givers or problem solvers. Coaches are not therapists or professional counselors. They are sensitive and careful listeners who have received special training to enable them to help other patients think through and solve the problems they may be experiencing.

As a patient, you have immense credibility with those who are struggling to adjust—often more than the unit staff and doctors. Because you have had similar experiences, you bring a level of understanding that is hard for others to replicate. When you add an accurate pool of knowledge about ESRD, and the skills and tools presented in this manual, you greatly increase your ability to help others.

QUALIFICATIONS

- Is a dialysis patient or a transplant recipient
- Demonstrates a positive attitude and adjustment to his or her life with ESRD
- Has effective communication skills
- Is able to relate successfully to individuals of various backgrounds and ages
- Has a desire to provide support and encouragement to ESRD patients and their families.

WHAT COACHES PROVIDE

- Knowledge of “how to” from personal experience
- Current information about kidney failure, transplantation and treatment
- Role modeling
- Access to professional staff
- A path to positive adjustment
- Tools to maximize quality of life for new dialysis patients and transplant recipient

QUALITIES OF A GREAT COACH

- Friendly and outgoing
- A listener and a learner—a coach gives the other person time to talk
- Non-judgmental toward the values and behaviors of the patient and/or family members
- Dependable in meeting time commitments
- Discreet - adheres to rules of confidentiality
- Someone who shows an honest interest in helping ESRD patients
- Flexible and open in discussion
- Non-directive and supportive
- Someone who assists in problem solving

WHAT COACHES SHOULD DO

- Refrain from answering medical questions or offering treatment advice but appropriately refer the person to professional staff (doctor, nurse, social worker).
- Remember dialysis facility and hospital etiquette.
 - If meeting in a dialysis unit, check in at the front desk. Follow unit procedures for entry into treatment area.
 - Consult with hospital/unit staff before meeting with the patient or family member. They need to know who you are and if it will be an appropriate time to visit.
 - Respect posted regulations—if in doubt, ask a nurse or a hospital staff member.

WHAT COACHES SHOULD NOT DO

A coach is not a therapist, social worker, physician, nurse, or dietitian. As such, coaches should not do the following.

- Suggest a diagnosis for medical problems
- Advocate a particular type of medical therapy
- Give advice
- Recommend care providers
- Overstay your welcome—be careful about timing and length of your visit
- Invade their privacy

COACH RESPONSIBILITIES AND EXPECTATIONS

- Be willing to learn
- Read the handbook and raise any questions
- Be non-judgmental toward problems presented
- Be open to constructive feedback, and use it for improving communication skills
- Give helpful positive and negative feedback to other trainees in a clear and precise manner
- Be prompt at scheduled appointments and meetings
- Provide appropriate information and emotional support to patients and families in a mature, empathic manner, using knowledge of coping skills and personal experience
- Maintain confidentiality of information gained because of this position
- Maintain on-going communication with Unit Social Worker or Coaching Supervisor
- Initiate and follow through with Coaching sessions and turn in any logs and/or paperwork required by unit in a timely manner
- Adhere to the policies and procedures of the unit including writing consultation reports and keeping a record of volunteer hours if required by unit
- Advocate for consumer rights and needs when appropriate
- Refer to other professionals as appropriate (social worker, dietician, physician, etc.)



10 COACHING GUIDELINES

1. **Respond promptly.** When you receive a referral, contact the person as soon as possible, definitely within 48 hours. If you are unable to contact them within 48 hours, contact the referral person to let him or her know.
2. **Know your limits.** If you cannot take a referral because of time or personal commitments, it is all right to say no.
3. **Respect other people's boundaries.** Set a meeting with the person at a time and place convenient for him or her, possibly in the dialysis unit, transplant center or hospital. Keep it informal and friendly. Be aware that he or she may feel uncomfortable talking to a stranger. Several phone contacts may help to build comfort prior to meeting in person.
4. **Announce any schedule changes.** If an emergency arises and you cannot keep your appointment, call the person right away and let him or her know that you need to reschedule. Follow up or reschedule as soon as possible.
5. **Listen carefully.** Remember that your primary responsibility is to be a good listener and to keep all matters confidential. You are not there to make judgments, give unsolicited advice, endorse specific programs, or to act as one who has all the answers or does everything right. You are to be supportive, encouraging, helpful and, most of all, understanding of what the person is going through.
6. **Take care of you.** Remember that a person adjusting to ESRD may find it difficult to feel positive about anything. It may be quite some time before he/she is able to appreciate the available services. If you feel the mentoring session is affecting your own outlook, schedule time with your own social worker or coaching coordinator.
7. **Be realistic.** Do not say, "This is not the end of the world." Do not promise that things will get better. You are a living example that things can get better, but do not make promises you cannot keep.
8. **Be honest.** Answer questions honestly, but be careful to point out that each person may respond differently to treatment.
9. **Share resources.** Bring informational literature. Offer it when you are sure that the materials are appropriate and they are ready to have that information. It may be more appropriate to share these things during a second or third visit.
10. **Allow space.** In all of your contacts, listen to what your referral has to say first. Allow them to express their feelings and ask their questions. Don't overwhelm them with your experiences.

PEER MENTORING BEST PRACTICES

- 1) Defining clear but flexible objectives
- 2) Meeting monthly for patient-run support groups
- 3) Inviting experienced patients to educate new patients
- 4) Motivating and introducing peers to each other in person and via email
- 5) Engaging peers in unit activities
- 6) Utilizing the NKF Peer Mentoring Program for a firm foundation
- 7) Meeting outside the dialysis unit to create normalcy and foster relationships
- 8) Using forms of support and communication like a patient newsletter, or bulletin board with encouraging messages from other patients, to build camaraderie



PREPARING TO BE A COACH

INTRODUCTION

In order to be an effective coach, you will need to understand your own strengths and weaknesses. This unit will help you gain a better understanding of yourself. Being honest with yourself about your abilities and your preferences will help your coaching experiences be both pleasant and productive.

One of the most crucial traits to coaching is your ability to respect and adhere to **Confidentiality**. We will examine this concept throughout the manual. Do not underestimate the importance of confidentiality; it is vital to the success of this program.



SELF REFLECTION

RELATING TO OTHERS

To be a good coach, it is important to understand how you relate to other people. Listed below are a number of behaviors that are essential to high-level human relating. Rate yourself on these behaviors.

EXERCISE: HOW I RELATE

| BEHAVIOR | SELF-RATING (Place an X in the box that you feel represents you) | | |
|--|---|----------|--------|
| | WEAK | ADEQUATE | STRONG |
| <p>Empathy: I see the world through the eyes of others; I understand others because I can get inside the skin of others; I listen well to all the cues, both verbal and nonverbal that the other emits and I respond to those cues.</p> | | | |
| <p>Warmth, respect: I express (and not just feel) in a variety of ways that I am “for” others, that I respect them; I accept others even though I do not necessarily approve of what they do; I am an actively supportive person.</p> | | | |
| <p>Genuineness: I am genuine rather than phony in my interactions; I do not hide behind roles or facades; others know where I stand; I am myself in my interactions.</p> | | | |

| BEHAVIOR | SELF-RATING (Place an X in the box that you feel represents you) | | |
|---|---|----------|--------|
| | WEAK | ADEQUATE | STRONG |
| <p>Concreteness: I am not vague when I speak to others; I do not speak in generalities nor do I beat around the bush; I deal with concrete experience and behavior when I talk; I am direct and specific.</p> | | | |
| <p>Initiative: In my relationships, I act rather than just react; I go out to contact others without waiting to be contacted. I am spontaneous, I take initiative with a wide variety of ways of relating to others; when in a group, I “own” the interactions that take place between other members and get involved with them.</p> | | | |
| <p>Immediacy: I deal openly and directly with my relationships to others; I know where I stand with others and they know where they stand with me because I deal with the relationships.</p> | | | |
| <p>Self-disclosure: I let others know the person inside, I am not an exhibitionist, but I use self-disclosure to help establish sound relationships with others; I am open without being a secret-revealer or a secret-search, for I am important, not just my secret.</p> | | | |
| <p>Feelings and emotions: I am not afraid to deal directly with emotion, my own or others; in my relationships, I allow myself both to feel and give expression to what I feel; I</p> | | | |

| BEHAVIOR | SELF-RATING (Place an X in the box that you feel represents you) | | |
|---|---|----------|--------|
| | WEAK | ADEQUATE | STRONG |
| expect others to do the same; but I do not inflict my emotions on others. | | | |
| Confrontation: I challenge others responsibility and with care; I use confrontation as a way of getting involved with others; I do not use confrontation to punish. | | | |
| Self-exploration: I examine my lifestyle and behavior and want others to help me do so; I respond to confrontation as non-defensively as possible; I am open to changing my behavior; I see confrontation as an opportunity for self-exploration. | | | |

Note that a rating of **strong** means that in a particular category, you would consider yourself a resource person (if only minimally so) in a human relationship or a group. If you feel that you rate **adequate** or **weak** in any category, you may need to be aware of this trait in yourself so that you can self-monitor how you are reacting to others.

Remember, that none of us are static and many outside influences (tired, frustrated, and underappreciated) may affect our feelings in any category. However, if you feel you are lacking in any category you may wish to do some additional study or exercises to help develop that skill and make it feel more natural.

SETTING YOUR PRIORITIES¹

There is not much separating the people who are happy and fulfilled from those who aren't. One is knowing your life purpose and what is it that you want out of life; to have a vision and some aims in life. Most people stumble through their lives, too occupied in anxiety about their day-to-day existence to think about the bigger picture.

Do you know what's ultimately important to you? It has been said that in life, nobody gets out of it alive. So the question is this: Do you know what you want to get out of life?

The other thing is identifying and setting your life priorities right. Having more awareness of them will aid you to achieve the things that really matter. If you don't know how much you want what you really want, how can you strive for it?

"The main thing is to keep the main thing the main thing."

~ Stephen R Covey

¹ Covey, Steven. 2014. 'Setting Your Life Priorities Right'. Blog. *Coaching-Journeys.Com*. <http://coaching-journey.com/2013/02/setting-your-life-priorities-right/>.

EXERCISE: SETTING YOUR PRIORITIES

The following is a pool of keywords representing **work-life priorities** that you may look for, in both your professional and personal life. Your task is to take these keywords and identify your priorities (you may also use your own keywords or add any that are not already there) in rank of importance to you.



Put the most important priorities at the top and the least at the bottom of your list. A good and easy way to do this is to write each priority out on a fresh Post-It note, and to keep reordering the list until you are satisfied with the rankings.

You are not allowed to have tied rankings. Life is often about making trade-offs. There are only 24 hours in a day and 7 days in a week. As much as we might like to have it all, the reality is that we're bound by the constraints of time, energy and resources.

If you want to pursue a higher income, would you trade off more leisure time? If you want more responsibility at work, how compatible is it with having more children?

Once you're done, look through the ordering and ask yourself "Am I happy with my list?"

Once you are happy with the ordering of your priorities list, you will have a better picture of what drives you in your life. This clearer self-awareness will allow you to make sharper

decisions, and do less with the unnecessary stress to increase your overall satisfaction and fulfillment in life.

The ordering of rankings in your priorities list may change over time. For example, “Spirituality” may become increasingly more meaningful and significant to you, as you grow older. Your current list is a snapshot of what you want in life right now and will serve as a compass in navigating your life.

Setting Life's Priorities²

By Ronda Devereaux

Every now and then, do the complexities and chaos in your life get the better of you? You know, those WHY ME moments! You might even struggle to figure out what's next. Maybe you feel confused about which way to go. Have you ever thought about setting life priorities to make your life easier?

When you're struggling to determine what's important to you, it's hard to make decisions. What needs to be done next? How should you spend your time? What will make the biggest impact? Even where you go for the evening can become a hard decision if you don't have your priorities defined.

Feeling torn between two or more people, places and things is common if you haven't yet identified your priorities. After all, when you consider everything and everyone in your life as all-equal in terms of their “level” of importance, it's going to be tough to choose what to do next.

Setting your life priorities is a way of identifying what's most important to you. Once you determine your priorities, you'll be surprised at how some decisions make up their own mind. You also have the peace of mind knowing that you did the right thing. There are also different priorities for different times. Your family may be a priority for you, but while you are at work—work should be your priority. That way you are giving your best to everyone when needed.

Establishing priorities also gives you a clearer focus on how to allot your time. If you allot the bulk of your time to doing what's most important with the most important people in your life, you'll feel more fulfilled and satisfied with your life experiences.

² Devereaux, Ronda. 2013. 'Setting Your Life Priorities'. Blog. *Choice Life Strategies*. <http://choicelifestrategies.com/setting-your-life-priorities/>.

Common Life Priorities

What might your priorities be? The possibilities are endless. In the list below, you'll find many common priorities in no particular order. Feel free to use the list as inspiration to help you figure out your own priorities.

- Family
- Finances
- Friends
- Extended family
- Work
- Hobbies
- Personal appearance
- Health and physical exercise/activities
- Healthy and nutritious eating
- “Alone-time” with partner
- Spending time alone
- Quality time with the children
- Your spiritual journey
- Education
- Playing games on the internet
- Connecting with friends
- Watching television

Example of a “Prioritized” Listing of Life Priorities

The whole idea of setting priorities is to put the many elements of your life into an order, with those that are most important to you at the top. Knowing your highest priority on the list is necessary in order to make wise, focused decisions that are right for you. Consider this next list, which is an example of someone’s life priorities.

1. Family
2. Alone-time with partner
3. Work
4. Health and physical exercise
5. Nutritious eating
6. Friends
7. Watching television
8. Personal appearance
9. Hobbies—movies and reading

ASSESSING YOUR ASSERTIVENESS

We, as functional members of society, strive to be Assertive but NOT Aggressive. Being assertive allows us to express our needs without trampling on the rights of others. This can often be a fine line, but it is necessary to achieving your goals without alienating those around you. The following section will help you to understand the difference between assertiveness and aggression.

Being assertive: Reduce Stress, Communicate Better³

By Mayo Clinic Staff

Assertiveness can help you control stress and anger and improve coping skills. Recognize and learn assertive behavior and communication. By Mayo Clinic Staff

Being assertive is a core communication skill. Being assertive means that you express yourself effectively and stand up for your point of view, while also respecting the rights and beliefs of others. Being assertive can also help boost your self-esteem and earn others' respect. This can help with stress management, especially if you tend to take on too many responsibilities because you have a hard time saying no. Some people seem to be naturally assertive. But if you're not one of them, you can learn to be more assertive.

Why assertive communication makes sense

Because assertiveness is based on mutual respect, it's an effective and diplomatic communication style. Being assertive shows that you respect yourself, because you're willing to stand up for your interests and express your thoughts and feelings. It also demonstrates that you're aware of the rights of others and are willing to work on resolving conflicts.

Of course, it's not just what you say — your message — but also how you say it that's important. Assertive communication is direct and respectful. Being assertive gives you the best chance of successfully delivering your message. If you communicate in a way that's too passive or too aggressive, your message may get lost because people are too busy reacting to your delivery.

³ MayoClinic.org,. 2014. 'Being Assertive: Reduce Stress, Communicate Better - Mayo Clinic'. <http://www.mayoclinic.org/healthy-living/stress-management/in-depth/assertive/art-20044644>.

Assertive vs. passive behavior

If your style is passive, you may seem to be shy or overly easygoing. You may routinely say things such as, "I'll just go with whatever the group decides." You tend to avoid conflict. Why is that a problem? Because the message you are sending is that your thoughts and feelings are not as important as those of other people. In essence, when you are too passive, you give others the license to disregard your wants and needs.

Consider this example: You say yes when a colleague asks you to take over a project, even though your plate is full and the extra work means you will have to work overtime and miss your daughter's soccer game. Your intention may be to keep the peace. However, always saying yes can poison your relationships. Worse, it may cause you internal conflict because your needs and those of your family always come second.

The internal conflict that can be created by passive behavior can lead to:

- Stress
- Resentment
- Seething anger
- Feelings of victimization
- Desire to exact revenge

Assertive vs. aggressive behavior

Now consider the other side. If your style is aggressive, you may come across as a bully who disregards the needs, feelings and opinions of others. You may appear self-righteous or superior. Very aggressive people humiliate and intimidate others, and may even be physically threatening.

You may think that being aggressive gets you what you want. However, it comes at a cost. Aggression undercuts trust and mutual respect. Others may come to resent you, leading them to avoid or oppose you.

NON-ASSERTIVE, ASSERTIVE AND AGGRESSIVE STYLES OF BEHAVIOR

Non-assertive is failing to stand up for oneself, or standing up for oneself in such an ineffectual manner that one's rights are easily violated.

Assertive is standing up for oneself in such a way that one does not violate the basic rights of another person. It is a direct, honest and appropriate expression of one's feelings and opinions.

Aggressive is standing up for oneself in such a way that the rights of the other people are compromised in the process. It is an attempt (conscious or unconscious) to humiliate or put down the other person.

| | Non-assertive | Assertive | Aggressive |
|--|--|---|--|
| Characteristics: | <i>Indirect, self-denying, hidden bargains, emotional dishonesty</i> | <i>Direct, Expressive, Leveling</i> | <i>Direct, domineering, at expense of others, cutting off communication, putting down others</i> |
| Your feelings when you engage in this behavior: | Hurt, anxious at the time, and possibly angry later. | Confident, self-respect at the time and later | Righteous, superior, condescending toward others at the time and possibly guilty later |
| The other person's feelings about her or himself when you engage in this behavior: | Guilty or superior | Valued, respected | Hurt, Humiliated |
| The other person's feelings toward you when you engage in this behavior: | Irritation, pity, disgust | Usually respect | Angry, vengeful |

EXERCISE: ASSERTIVE BEHAVIOR ASSESSMENT

The following questions will help assess your assertiveness. Circle the number that best describes you. If an item describes a situation unfamiliar to you, try to imagine what your response would be. Be honest in your responses.

| QUESTION | NEVER (1) | SOMETIMES (2) | ALWAYS (3) |
|--|--------------|------------------|---------------|
| I am poised and confident among strangers. | | | |
| I accept compliments and gifts without embarrassment or a sense of obligation. | | | |
| I freely express my admiration of others' ideas and achievements. | | | |
| I take the initiative in personal contacts. | | | |
| When I have done something well, I tell others | | | |
| When I need help, I ask others to help me. | | | |
| When I am at fault, I apologize. | | | |
| When I like someone very much, I tell him or her so. | | | |
| When confused, I ask for clarification. | | | |
| When someone cuts in front of me in line, I protest. | | | |
| When I am lonely or depressed I take action to improve my mental outlook. | | | |
| When working at a job or task I dislike intensely, I look for ways to improve my situation. | | | |
| I complain to the management when I have been over-charged or have received poor service. | | | |
| When something in my house or apartment malfunctions, I see that the property owner replaces it. | | | |
| When I disturbed by someone smoking, I say so. | | | |
| I ask my doctor all of the questions that I want answered. | | | |
| I ask for directions when I need help finding my way. | | | |
| I make sexual advances toward my spouse or sexual partner. | | | |
| When I discover that I have purchased defective merchandise, I return it to the store. | | | |
| When people talk too loud in a theater, lecture or concert, I am able to ask them to be quiet. | | | |
| I maintain good eye contact in conversations. | | | |
| I would sit in front of a large group if the only remaining seats were located there. | | | |
| When interrupted, I comment on the interruption and | | | |

| QUESTION | NEVER (1) | SOMETIMES (2) | ALWAYS (3) |
|---|--------------|------------------|---------------|
| then finish what I am saying. | | | |
| When I miss someone, I express the fact that I want to spend more time with that person. | | | |
| When a friend invites me to join him or her and I really don't want to, I turn down the request. | | | |
| When a friend calls and talks too long on the phone, I can terminate the conversation effectively. | | | |
| When someone criticizes me, I listen to the criticism without being defensive. | | | |
| I speak up readily when I am in a group situation. | | | |
| I tell my children the things I like about them. | | | |
| When someone completes a task or job for me which I am dissatisfied, I ask that it be done correctly. | | | |

HOW CAN YOU TELL WHEN YOU ARE UNDER-ASSERTIVE OR OVER-ASSERTIVE?

Non-Assertive Behavior

You are under-assertive when you...

- Don't stand up for your own rights
- Let other people take unfair advantage of you
- Don't express your views and feelings
- Feel guilty when you do not stand up for your rights or express your feelings
- Are unable to make reasonable requests of other people
- Are unable to start or carry on conversations comfortably
- Are unable to recognize and express your good points

Aggressive Behavior

You are over-assertive when you...

- Forget about another person's rights
- Take unfair advantage of other people
- Make other people look or feel stupid, small or afraid
- Become abusive when you are angry with someone or when you are criticizing someone
- Make unreasonable demands on other people
- Brag obnoxiously and make unrealistic claims about your good points
- May feel good at first but guilty later

Assertive Behavior

You are appropriately assertive when you...

- Stand up for your own rights and let other people do the same
- Can say no when you don't want to say yes to someone's request
- Can express positive feelings about other people and what they do
- Can express negative feelings about other people and what they do without being abusive or cruel
- Can take compliments without denying them
- Can take criticism without getting defensive
- Can start and carry on conversations
- Can recognize and express your good points
- Can ask for what is rightfully yours
- Feel good about yourself, in control after any of the above

- Q.** Does being appropriately assertive mean you win or get your way all the time?
- A.** No, often it means you compromise and not feel you have lost. Often it means you increase your chances to work things out to your satisfaction later even if you aren't satisfied completely now.
- Q.** Does "expressing your views and feelings," mean you may say whatever is on your mind? Do you just let your emotions go all the time, all over the place, with everyone?
- A.** No, for example, you may get **temporary** satisfaction if you tell the boss to go to hell, but the **long-range** effect could you losing your job.
- Q.** How do I decide when to be assertive?
- A.** That is up to you. You are free to choose not to assert yourself.

If you feel that you are being assertive, ask yourself the following three questions.

1. How important is this to me?
2. How will I feel afterward?
3. How much will it cost me? (Don't scare yourself with irrational assumptions or unlikely probabilities. Be realistic.)

BASIC HUMAN RIGHTS

An important part of assertiveness training is the identification of basic human rights. It is essential that these rights be identified because all too often we do not really believe that we have to develop, cherish and express feelings, beliefs and opinions.

The following list, compiled from the reading list of Spector and Smith, contains 19 basic human rights. This list is by no means exhaustive; however, it is presented to you in order to stimulate your thoughts and to enhance your assertive behavior.

- Right to refuse without having to feel guilty or selfish
- Right to feel and express anger
- Right to feel and express and healthy competitiveness and achievement drive
- Right to strive for self-actualization through whatever ethical channel is appropriate for your talents and interests
- Right to use your judgment in deciding which needs are the most important to meet
- Right to have your opinion given the same respect and consideration that other people's opinions are given
- Right to be independent
- Right to offer no reasons or excuses for justifying your behavior
- Right to judge your own behavior, thoughts and emotions, and to take the responsibility for their initiation and consequences
- Right to change your mind
- Right to make mistakes and be responsible for them
- Right to say, "I don't know"
- Right to say, "I don't understand"
- Right to say, "I don't care"
- Right to be sensitive to another's needs, without being responsible for them
- Right to tell someone what your needs are
- Right to have an opinion that may be different from the opinion of others

KNOW YOUR LIMITS

It is ok to think about you: your time constraints and your health priorities.

1. Accept personal responsibility for your own well-being.
2. Don't take things personally—there are no failures.
3. Respect the individuality of the person. If you cannot relate or work with the referral, be honest, talk to your facilitator.
4. Stick to your coaching role.
5. Never offer financial assistance.
6. If in doubt, don't do it. Check with your facilitator.
7. Review the manual as often as needed.
8. Never do for others what they can do for themselves.
9. It's okay to say, "I don't know." Follow up with, "let's find out."
10. Be aware you are an observer and participant in the relationship.
11. Be alert to not only the person's behavior, but also your own reactions and behavior.
12. Keep in mind the primary task is helping people.
13. You will be affected by a patient's death. Talk with your Social Worker.
14. Allow people to express their negative feelings without taking them on.

TAKING CARE OF YOU

1. Remember to take time to care for the things you need.
2. Remember that you are not a magician. You cannot change anyone else, only how I relate to him or her.
3. Learn to both give and receive encouragement.
4. Remember that in light of all the pain we see, we are all bound to feel helpless at times.
5. Focus on the good that has occurred during the day.
6. Be a resource for you—try new things.

Truly listening to others is a gift to them. . . Give it freely.

Taking care of your self is a gift. . . Do it daily.

WHAT ALL COACHES NEED TO KNOW

CONFIDENTIALITY

What is confidentiality?

Keeping information confidential means that you make a promise not to share anything with anyone at any time. This means EVERYONE, including your spouse, family, friends, other patients, co-workers, strangers- everyone.

Everyone has a right to keep personal information to him or herself. It is a person's choice, not an obligation, to share information. Keep in mind that much of the information a person may share with you may be sensitive, embarrassing, or potentially stigmatizing to them.

Why is confidentiality important?

It protects a person's right to keep information about them private, and it establishes trust in the coaching relationship. Trust is essential to establish a positive and effective coaching relationship. If a person doesn't trust you, he/she won't share with you. In that case, you can't be helpful. When you assure a person that what they share stays with you, that it is confidential, you are creating trust. It's not anyone else's business.

Temptation to Talk

There will be times when you feel like you cannot keep it to yourself. Gossip can be harmful; control yourself and do not do it. If you need to vent, talk with other coaches, a social worker, or a transplant/dialysis nurse. You can do so *without using names or other identifying information*.

Vague generalities can be okay when used to illustrate a point or provide an example. However, use caution not to mention anything that could identify a person and remember that the more you talk, the easier it becomes to slip and break confidentiality.

If a person has an exceptional experience or concept, you might ask for permission to share the experience/concept without mentioning names.

Documentation/Paperwork

- If your unit requires/requests coaching logs, keep all paperwork related to individuals in a private location.
- It should NOT be out in the open where someone could just “stumble” upon it.
- Keep your log sheets in a covered notebook in a place where there isn’t a lot of traffic or a chance that someone could find it when looking for something else.

Exceptions of the Confidentiality Rule

It is a good idea to let the patient know at the beginning that you intend to maintain confidentiality at all times, but let him/her know of the exceptions.

1. If someone tells you something that indicates he or she may be in danger, you cannot ignore it, pretend you did not hear it, or keep it to yourself. Examples: talk of suicide, domestic abuse of any sort, stopping medical treatment, trying an untested, alternative medical treatment, etc.
2. Let the person know that you are concerned about what they are saying. Encourage them to discuss it with someone—their family, doctor, social worker, or nurse. If they refuse, let them why this is an instance you cannot keep the information confidential. Let them know what you are going to share, who you will share it with and why.
3. Immediately contact the Social Worker/Coaching Supervisor or someone from the person’s treatment team and share your concerns.
4. If at any time you are unsure about reporting your concern, you can contact the social worker to discuss the situation without using names or identifying information.

COMMUNICATION SKILLS

ACTIVE LISTENING

Active listening is the process by which you show that you understand what is being said, give and receive feedback, and show non-judgmental and supportive caring. Active listening is not an easy skill to master, but once you have learned and practiced the skill, you will find it helpful in all your life relationships.

Listening opens the door to meaning. When you can hear the person, understand his or her situation and feelings, then you are in a position to reply in a way that makes sense. By listening, you allow the other person look at, and sort out, their problems. It aids them in considering solutions. Listening is hard work. It requires your concentration, willingness and practice.

EXERCISE: REVIEW THE FOLLOWING LIST OF LISTENING AND NON-LISTENING BEHAVIORS

| Listening Behaviors | Non-listening Behaviors |
|---|--|
| Looking into speaker's eyes | Interrupting speaker |
| Touching speaker's hand /arm (if appropriate) | Keeping a "poker face" (no expression) |
| Leaning toward speaker | Expressing boredom through tone of voice |
| Maintaining a pleasant facial expression | Staring at speaker |
| Changing facial expression in response to speaker's message | Yawning/Stretching |
| Sitting directly facing speaker | Leaning away from speaker |
| Nodding head affirmatively | Looking at ceiling/floor |
| Keeping eyes wide open | Glancing at watch/clock |
| Raising eyebrows | Inspecting fingernails/cracking knuckles |
| Using expressive hand gestures | Giving immediate attention to any interruption |
| Giving fast glances | Fidgeting (tapping foot or finger) |
| Communicating appreciation/interest | Crossing arms across chest |
| Pausing before you respond | Sneering/eye rolling |

Principles of Active Listening

The basic goal of active listening is to give the person a chance to express, explore and understand his or her own feelings. Two elements are essential to achieve this goal.

1. The awareness that you cannot solve someone's problems, but that the person must do that for himself or herself
2. That an individual cannot change a situation or solve a problem until the person is aware of his or her own feelings about that problem

Keep the following things in mind when you are listening to the other person.

- **Switch places:** try to understand what the other person is saying, not what you would say in the same situation.
- **Listen more than you talk:** listen closely for statements about feelings; be patient and do not push. Ask open-ended questions, leaving room for the person to go in the direction that is most important to him or her.
- **Respect their right to privacy:** don't impose your own feelings and attitudes on the consumer. Be non-judgmental; a solution that is right for you may be wrong for them.

Empathic Listening⁴

Active Listening is sometimes called empathic listening. Empathy is the ability to understand another person's ideas and feelings. Empathetic listening is gaining an understanding through listening and demonstrating that you understand by responding.

- **THE OTHER PERSON SETS THE PACE.** You let them take the lead in the conversation. You don't push them faster than they want to go. This builds trust.
- **THE OTHER PERSON IS COMPLETELY FREE TO BE NATURAL.** That is a rare opportunity. The other person will probably take advantage of it by relaxing and behaving in the ways that are most real and honest. When you show that you can be trusted, the others are free to tell you about their hurts, secrets and ambitions. The result—you can really know them.
- **THE OTHER PERSON GAINS SELF-UNDERSTANDING.** In a mirror, you can see things about your physical self that cannot otherwise be seen. In the same way, empathic listening serves as a mirror in which person can see their behaviors and attitudes more completely. This helps them understand themselves better and forces them to decide whether or not they like themselves the way they are or if they want to change.

⁴ Peavy, Vance. 1977. *Empathic Listening Workbook*. [Victoria, B.C.: Adult Counselling Project, University of Victoria.

Common Mistakes in Empathic Listening

- Sounding like a parrot or robot
- Talking about content only and ignoring feelings.
- Giving cheap advice
- Using poor attending skills: You sound good, but you look like you couldn't care less
- Shifting the attention to you, talking instead of listening
- Having no energy. You must be as intense in your words and emphasis as the other person
- Sliding into non-helpful replies such as joking, making judgments, reassuring, etc.

Listen

When I ask you to listen to me and you start giving advice, you have not done what I asked. When I ask you to listen to me and you begin to tell me why I shouldn't feel that way, you are trampling on my feelings. When I ask you to listen to you and me feel you have to do something to solve my problems, you have failed me, strange, as that may seem.

Listen! All I asked was that you listen not talk. Advice is cheaper.

And I can do for myself, I'm not helpless. I may be discouraged and faltering, but not helpless. When you do something for me that I can and need to do for myself, you contribute to my fear and weakness.

But when you accept as a simple fact that I do feel and what I feel, no matter how irrational, then I quit trying to convince you and can get about the business of understanding what's behind this irrational feeling. And when that's clear, the answers are obvious and I don't need advice. Irrational feelings make sense when we understand what's behind them.

Perhaps that is why prayer works, sometimes for some people, because God is mute, and doesn't give advice or try to fix things.

So, please listen and just hear me, and if you want to talk wait a minute for your turn, and I'll listen to you.

~Anonymous

COMMUNICATING WITH PEOPLE IN CRISIS⁵

- They often do not hear, or cannot retain, many facts.
- They may reveal more about themselves than they are comfortable having other people to know.
- It may seem that they have lost control of their life.
- They may find it difficult, or even impossible, to make decisions.
- They may expect you to make decisions for them or give them direct advice.
- They may need to ventilate and express feelings, such as anger.
- They will have their own internal agenda for your meeting and may not hear what you say accurately.
- They may view you as some kind of expert, assuming that you will have all of the right answers.
- They may feel very vulnerable and give you more power than you deserve or feel comfortable with.
- They may seem to have some very unrealistic ideas or expectations for themselves and/or their family.
- They may ask questions being prepared for the answers.
- They may resent your ability to survive



⁵ Iscoe, Louise, and Karen Bordelon. 1985. 'Pilot Parents: Peer Support For Parents Of Handicapped Children'. *Children's Health Care* 14 (2): 103-109. doi:10.1207/s15326888chc1402_6.

COMMUNICATION TECHNIQUES

| TERM | EXPLANATION |
|-------------------------------|---|
| "I" Statements | Owning your own perceptions or feelings about a situation, and sharing these when appropriate with the person; giving the individual the benefit of another person's point of view, clearly labeled as your own, to accept, reject or consider; this can be your reaction either to the person or to his or her situation. |
| Accepting | Conveying to the person that this is a safe place where he or she can say whatever is needed, no matter what your viewpoint; the person needs to be allowed to express his or her feelings (sometimes for the first time) before ever being able to control his or her problems. |
| Attending | The small noises one person makes to another to show interest and concern; serves the same purpose as a nod or smile, shows the person that you are awake and listening without interrupting his/her train of thought. |
| Confronting | Describing the person's behavior and adding your own feelings about the behavior, then checking this perception with the individual. One individual may have well-established self-destructive ways of behaving, another will try to remain helpless without taking steps to help him or herself. A gentle confrontation regarding his or her behavior will place the responsibility to act back on the individual. |
| Focusing | Providing leads for the person to elaborate on points which seem to be significant; aiding the individual in moving from the general to the specific; encouraging the person to zero in on the here and now; someone in crisis is frequently so overwhelmed by these problems that he or she cannot take enough control to see the specifics of the problem; focusing techniques help the person name problems so that he or she may concretely tackle them |
| Open-ended Questioning | Opening up a broad topic area for a person to address if he or she chooses; basically consists of phrasing a question in such a way that it cannot be answered with one word, like yes or no; by far the largest number of questions you ask should be open-ended to give the person permission and encouragement to discuss and issue, without suggesting that there is a specific answer, the counselor wants to hear (e.g., "How did you feel about that?" "Weren't you angry?") |

| TERM | EXPLANATION |
|--------------------------------|--|
| Paraphrasing | Stating in your own, hear words what the person's remarks convey to you. Listen to the basic message; restate a summary of that message; check with the individual if your paraphrase is accurate; paraphrasing give shape to what the person may perceive as an overwhelming, nebulous threat. It helps focus the problem on a level where it can be examined and dealt with. |
| Parroting | Repeating word for word what the person has just said, giving the person the chance to hear him or herself in a fresh way; forcing the individual to clarify himself or recognize exaggeration; also useful as a stalling device or if your mind goes blank. |
| Recognizing Ambivalence | Identifying with the person's strong feelings on both sides of an issue and encouraging him or her to specify these feelings in order to resolve them; anyone who has ever faced a difficult decision will at some point have ambivalent feelings; naming and exploring these feelings will empower him or her to settle on the best decision. |
| Self-disclosure | Briefly giving the individual person information about yourself, other than the facts that would identify you personally |
| Silence | Exactly that; either you or the person may need to take some time to ponder; allowing silence is also a great way to force the other person to take the initiative for the conversation. Don't fall into the trap of thinking that someone has to be talking all the time, that is simply not so. |

ROADBLOCKS TO COMMUNICATION

| Roadblock | Sample Statements | Possible Effects |
|---------------------------------------|---|---|
| Ordering, commanding | <p><i>"You must ... ,"</i></p> <p><i>"You have to ... ,"</i></p> <p><i>"You will ..."</i></p> | <ul style="list-style-type: none"> • can produce fear or actual resistance • invites testing • promotes rebellious behavior, retaliation |
| Warning, Threatening | <p><i>"If you don't, then ..."</i></p> <p><i>"You'd better, or ..."</i></p> | <ul style="list-style-type: none"> • can produce fear, submissiveness • invites testing of threatened consequences • can cause resentment, anger, rebellion |
| Moralizing, Preaching | <p><i>"You should ...,"</i></p> <p><i>"You ought to ...,"</i></p> <p><i>"It is your responsibility ..."</i></p> | <ul style="list-style-type: none"> • creates obligation or guilt feelings • can cause a person to dig in and defend his or her position even more (i.e. "Who Says?") • communicates lack of trust in a person's sense of responsibility |
| Advising, Giving Solutions | <p><i>"What I would do is ..."</i></p> <p><i>"Why don't you ..."</i></p> <p><i>"Let me suggest ..."</i></p> | <ul style="list-style-type: none"> • can imply that the person is not able to solve his or her own problems • prevents a person from thinking through a problem, considering alternative solutions and trying them out • can cause the person to feel inferior, inadequate |
| Persuading with Logic, Arguing | <p><i>"Here is why you are wrong ..."</i></p> <p><i>"The facts are ..."</i></p> <p><i>"Yes, but ..."</i></p> | <ul style="list-style-type: none"> • provokes defensive position and counter-arguments • often causes a person to turn off speaker, to quit listening • can cause the person to feel inferior, inadequate |
| Judging, Criticizing, Blaming: | <p><i>"You are not thinking maturely ..."</i></p> <p><i>"You are lazy ..."</i></p> | <ul style="list-style-type: none"> • implies incompetence, stupidity, poor judgment • cuts off communication from a person over fear of negative judgment or bailing out • person often accepts judgments as true ("I am bad") or retaliates ("You're not so great yourself!") |

SELECTIVE SHARING⁶

The sharing of personal experience is one of the most effective tools that a volunteer can use in supporting and encouraging another person. It is important, however, to be selective when deciding what parts of your own story to tell. Here are some specific guidelines to selective sharing.

There is a specific order to how one should proceed when meeting with the referred patient. Listen, think and then speak. This order is especially important to the selective sharing process.

Listen

Listening is more important than anything else in providing support is. Before sharing your own story, listen and be aware of how the patient is talking. What words are they using? What terms do they seem to avoid? For example, using very sick instead of critical or using tired instead of anemic.

Listening carefully can also help in discovering what the patient has already been told about their situation by professionals or other sources. Understanding what a patient already knows (or assumes) is critical to a coach's ability to be supportive in an appropriate way.

Think

Before responding to a patient's questions or request for information, stop and think about what you felt like at this stage in your own experience. It's easy to forget that the words we use the adjustments we've made and the way we handle our situations may be markedly different from the way we originally responded. Always be sensitive to the rawness of a patient's pain and be in touch with how far you have come in the adjustment process. Before sharing your story, try to remember back to the early days.

Speak

The referred patient will probably want to know about your experience. Here are a few things to remember when sharing.

- Qualify everything: "every patient is different", or "you may respond differently"
- Don't make promises
- Make sure that the patient is hearing what you are actually saying
- Are they asking questions that they don't really want to hear the answers to?
- Encourage them to check specific questions or concerns with a professional.

⁶ Iscoe and Bordelon, 1985

VALUES, BELIEFS, AND FEELINGS

VALUES: UNDERSTANDING OTHER PERSPECTIVES

Another vital concept for effective coaching is that you understand the other person's values. Values are those personal beliefs that motivate you and define what is important in your life. Values vary dramatically from person to person.

In your coaching, you will need to set your own values aside, learn to recognize and understand the other person's values, and respond to their rather than your own. This can be very difficult to do at first, but with practice, you will be able to notice when your own personal values are interfering with your performance as a coach.

It is very important to understand that what is a deal-breaker for one person may not be an issue at all for another. For example, a person who has been very physically active in their life and cannot sit still for five minutes at a time may find it very difficult to sit in a dialysis chair for 3 or 4 hours. Another person may be very content to sit and read for that amount of time.

You cannot expect others to react in the same way you reacted when faced with certain restrictions. You must work to understand their personal values, and help them look at the situation.

Examining values and then turning them into a priority list, is a good method of identifying what is most important in life, and what deserves the most attention first. Later in this section, we will look at how to prioritize values.

FEELINGS: WHAT DO THEY HAVE TO DO WITH COACHES?

It is essential to identify and deal with your feelings about ESRD so that you can help others to deal with their feelings. If you, as a Coach, have not been able to identify and express your feelings about your particular loss, and accept yourself in doing so, you will not be able to accept someone else's need to grieve.

"I would not be an okay person if I were to cry or be angry about my ESRD." If you believe that statement is true for you, then you will invariably transmit that value to your mentee. You will inhibit them from dealing with their own feelings. It is crucial that we never judge a person for having a feeling. If you are judgmental toward yourself for having feelings, you will judge others similarly.



It is important that throughout this training, you continue to identify your feelings and validate them so you can do the same for others in the future. Validating feelings comes from the belief that there is no such thing as a wrong feeling. A feeling cannot physically harm, kill or do damage to anyone. It has no rightness or wrongness to it. It just is. Denying a feeling can cause a person stress; verbalizing a feeling can cause relief. **"There is no feeling that is wrong."** If you believe this statement, it will be much easier to accept both personal feelings and the feelings of others.

RESPONDING TO FEELINGS-EMPATHY

Perhaps the most important section of this manual is this section on responding to feelings. It will demonstrate a tried and true method for defusing a tense and angry situation. Learning to recognize anger in a person and acknowledging that anger allows the person you are coaching to stop trying to prove their anger and start working through it.

Empathy is the ability to sense how people feel about something. Responding to feelings refers to the action, verbal or non-verbal cues by which we communicate empathic understanding to people about their feelings.

You can respond to feelings in three ways:

1. **Make a mental note** of the feeling but decide to make no verbal response to it, and go one with the discussion.
2. **Indicate that you recognize and understand** the feeling by saying so and then go on with the discussion.
3. **Stop the discussion, and focus** on the feeling or the issue that caused it. You can attempt to work on the emotion so that the person:
 - has it under control
 - has **explored** it enough so that he or she can focus on what to do about the things that evoke those feelings
 - has resolved the issue—then continue the discussion

It is important to know how to do the following.

- **Recognize the feeling.**
- **Relate and Respond to the feeling.**
- **Confirm the accuracy of your response.**

Recognizing

Attending is required to recognize the feeling. Attending not only to what is being said, but also to how it is being said and to the speaker's body language. The feeling can often differ from what he or she says. It is also useful to attend to your own feelings; they may serve as clues to what is going on in others.

For example, if **you** are feeling anxious, you should ask yourself if the person you are with is making you feel anxious. If so, you have to recognize that he or she may be feeling angry, or

perhaps you are feeling anxious in response to the same thing that is making the person anxious.

Relating and Responding

The second part of the task is to put the feelings into words, at least to yourself so that you can identify them. There are several ways to do this.

- Compare the feelings you have recognized in others with similar feelings that you have had.
- Compare the current feeling with feelings you have experienced in the past, and then recall what brought them on.

Confirming Accuracy

The third part of the task is to check out the accuracy of your observation and description with the individual you are trying to understand. You can do this with empathic responding. This works best when you:

1. Begin your statement tentatively, allowing for correction by the other person. For example, “I get the feeling that”, “I wonder if you are”, or “I hear you saying this”
2. Then you make specific reference to the feeling, selecting the word or phrase that most accurately reflects the feelings that you are trying to describe. The choice of words is very important here to reflect accurately the other person’s feelings.

For example, look at the subtle but important differences between each of the following words.

| | |
|----------------|----------------|
| Angry | Mad |
| Furious | Peeved |
| Annoyed | Enraged |

3. Relate the feeling to a specific something, someone, or situation.

For example, “It seems to me that you’ve been feeling very lonely ever since your friend moved away.”

How should I respond?

| | |
|---|--|
| <p>Some occasions when you only make a mental note</p> | <ul style="list-style-type: none"> • Identification of the feelings would embarrass the individual by calling attention to his or her behavior • You or the other person have become so emotional about something that it would throw the discussion off the topic |
| <p>Some occasions when you simply acknowledge feelings</p> | <ul style="list-style-type: none"> • The other person seems willing to share his or her feelings • The feelings are too strong or too apparent to be overlooked |
| <p>Some occasions when you discuss the feelings</p> | <ul style="list-style-type: none"> • The other person has expressed important feelings, and you believe that discussing them will help the person progress towards his or her goals • Interaction will be blocked until the feeling behind an issue is communicated and resolved |

How do you know that you have responded to feelings correctly?

- When the individual verifies it by agreeing with you
- When the individual is able to openly discuss his or her feelings
- When the atmosphere of the relationship is comfortable
- When the individual maintains his or her level of participation

CATEGORIES OF FEELINGS

Below you will find a list of some of the emotions you will come up against and their different forms. Familiarizing yourself with these feelings will help you to identify them in others.

| Type of Feeling | Level of Intensity | | |
|-----------------|--|--|--|
| | Powerful | Mild | Weak |
| Happy | <ul style="list-style-type: none"> • Excited • Elated • Overjoyed | <ul style="list-style-type: none"> • Cheerful • Up • Good | <ul style="list-style-type: none"> • Glad • Content • Satisfied |
| Sad | <ul style="list-style-type: none"> • Hopeless • Sorrowful • Depressed | <ul style="list-style-type: none"> • Upset • Distressed • Down | <ul style="list-style-type: none"> • Sorry • Lost • Bad |
| Angry | <ul style="list-style-type: none"> • Furious • Seething • Enraged | <ul style="list-style-type: none"> • Annoyed • Frustrated • Agitated | <ul style="list-style-type: none"> • Uptight • Dismayed • Put-out |
| Scared | <ul style="list-style-type: none"> • Fearful • Panicky • Afraid | <ul style="list-style-type: none"> • Threatened • Insecure • Uneasy | <ul style="list-style-type: none"> • Timid • Unsure • Nervous |
| Confused | <ul style="list-style-type: none"> • Bewildered • Trapped • Troubled | <ul style="list-style-type: none"> • Mixed-up • Groggy • Disorganized | <ul style="list-style-type: none"> • Bothered • Undecided • Uncommitted |
| Strong | <ul style="list-style-type: none"> • Potent • Super • Powerful | <ul style="list-style-type: none"> • Energetic • Confident • Capable | <ul style="list-style-type: none"> • Sure • Secure • Durable |
| Weak | <ul style="list-style-type: none"> • Overwhelmed • Impotent • Small | <ul style="list-style-type: none"> • Incapable • Helpless • Insecure | <ul style="list-style-type: none"> • Shaky • Unsure • Soft |

PROBLEM SOLVING

It is vitally important that you do not take on the role of problem solver. Your role as Coach is to help the other person identify an underlying problem, and help them work through the steps for effective problem solving.

Problem solving can be useful in all aspects of your own life as well as the lives of those you are coaching. Problem solving is not a one-size-fits-all process. Your first solution is seldom the best solution. However, with practice you will become more able to judge which solutions are most apt to be effective.

Five-Step Problem Solving

1. Identify and define the problem or issue.
What is it?
 - How and when does that happen?
 - How often?
2. Explain the problem or issue.
 - What would solving the problem accomplish (your objectives?)
 - What keeps you from solving the problem? (What rewards are there for staying the same?)
 - What is the price for not solving the problem?
3. Choose a next step.
 - Consider possible solutions and decide what is the best solution to try according to your feelings and values.
4. Act upon your choice.
 - What must you do to carry it out?
 - What support, if any, will be needed?
5. Evaluate the results.
 - What if your solution doesn't work?

ENHANCING YOUR PROBLEM SOLVING SKILLS⁷

1. Focus on the solution—not the problem

Neuroscientists have proven that your brain cannot find solutions if you focus on the problem. This is because when you focus on the problem you're effectively feeding 'negativity' which in turn activates negative emotions in the brain. These emotions block potential solutions. I'm not saying you should 'ignore the problem'—instead try and remain calm. It helps to first acknowledge the problem and then move your focus to a solution-oriented mindset where you keep fixed on what the 'answer' could be instead of lingering on 'what went wrong' and 'who's fault it is.'

2. Have an open mind

Try and entertain 'ALL POSSIBLE SOLUTIONS'—even if they seem ridiculous at first. It's important you keep an open mind to boost creative thinking, which can trigger potential solutions. Coming from 10 years in the corporate advertising industry it is drummed into you that 'No idea is a bad idea' and this aids creative thinking in brainstorming and other problem-solving techniques. Whatever you do—do not ridicule yourself for coming up with 'stupid solutions' as it's often the crazy ideas that trigger other more viable solutions.

3. View problems neutrally

Try not to view problems as 'scary' things! If you think about it what is a problem? It's really just feedback on your current situation. All a problem is telling you is that something is not currently working and that you need to find a new way around it. So try and approach problems neutrally—without any judgment. If you get caught up in the label 'problem' this may trigger a bought of negative thoughts and block any potential solutions from popping up!

4. Think laterally

Change the 'direction' of your thoughts by thinking outside the box. Pay attention to the saying, 'You cannot dig a hole in a different place by digging it deeper.' Try to change your approach and look at things in a new way. You can try flipping your objective around and looking for a solution that is the polar opposite! Even if it feels silly, a fresh & unique approach usually stimulates a fresh solution.

⁷ B, Zoe. 2014. '6 Ways To Enhance Your Productivity'. Blog. *Lifhack*. Accessed November 18. <http://www.lifhack.org/articles/productivity/6-ways-to-enhance-your-problem-solving-skills.html>.

5. Use language that creates possibility

Lead your thinking with phrases like 'what if ...' and 'imagine if ...' These terms open up our brains to think creatively and encourage solutions. Avoid closed, negative language such as 'I don't think ...' or 'This is not right but ...'

6. Simplify things

As human beings we have a tendency to make things more complicated than they need to be! Try simplifying your problem by generalizing it. Remove all the detail and go back to the basics. Try looking for a really easy, obvious solution—you might be surprised at the results! And we all know that it's often simple things that are the most productive.

INTERVIEWING AND PROBING

A good problem-solving process always begins with the information gathering. Interviewing is a technique for getting information from the consumer that will be helpful to the coach as he or she tries to identify the person's problem. The person having the problem must be the one to provide the information relevant to his or her problem.

Factors in Interviewing:

Collecting this specific information requires an interviewing process that is non-directive and supportive. The interviewer must establish a comfortable climate and use techniques/body language that promote an open discussion. Generally, there are two significant factors in any interview situation:

- First, the coach must establish a degree of rapport with the patient. That is, the patient should be made to feel comfortable in the discussion. Perhaps the best way to do this is for the coach to initially present him or herself as openly as possible: Who he or she is; why he or she is there; what he or she is doing; what he or she hopes to accomplish; and how the information will be used for.
- Second, the patient should do most of the talking. While this principle is true for almost any interview situation, and seems obvious, it is surprising how often a coach will take up more time than the patient will. Limit the majority of coach participation to building the initial rapport. This can take longer with some people than others who want to build a first step level of trust. Afterward, the coach may be even be puzzled to find that relatively little information was obtained. In a general information-gathering interview, this factor becomes extremely important. During the first half of the session, the coach should avoid asking directive questions.

Stimulating Discussion: Probing

One of the most challenging and important aspects of the coach's work is probing. The quality of the interview depends a great deal on the coach's ability to probe meaningfully and successfully.

Probing is the technique used by the coach to stimulate discussing and obtain more information. A question has been asked and an answer given. For any number of reasons, an answer may require the coach to seek more information to meet the objectives. Probing is the art of getting this additional information without directing or leading responses. A probe is usually just a few words that encourage the patient to expand the answer.

Probes have two major functions:

- Probes motivate the patient to communicate more fully so that he or she expands, clarifies, or explains what he or she has said.
- Probes focus on the discussion on the specific content of the interview so that irrelevant and unnecessary information can be eliminated.

Probes must perform these two functions without introducing bias by avoiding the introduction of unplanned and unwanted influences



Remember that probing should motivate the patient to communicate more fully and focuses the discussion on specific topics. These two things must be done without introducing bias.

The potential for bias is great in the use of probes. Under the pressure of the interviewing situation, the coach may unintentionally imply that some responses are more acceptable than others are.

Once the patient is communicating openly, information comes to the surface that helps identify the problem. When this happens, both patient and coach can move toward resolution, mutual growth, and development.

Kinds of Probes

As a coach, you may use several different techniques to stimulate a fuller, clearer response. These should appear naturally and casually in the conversation.

| Technique | How to Implement |
|---|---|
| <p>A brief assertion of understanding interest</p> | <p>By saying such things as “Uh-huh,” “I see,” “yes,” or “that’s interesting,” the coach indicates that he or she has heard the response, is interested in it, and expects more. These things stimulate the conversation.</p> |
| <p>An expectant pause</p> | <p>The simplest way to convey to a person that you know he or she has begun to answer the question, but that you feel he or she has more to say, is to be silent. The pause, often accompanied by an expectant look or nod of the head, allows the person time to gather his or her thoughts.</p> <p><i>Note: The coach must be sensitive to each individual in using this technique. Some respondents may be truly out of ideas, and a pause cannot always stimulate them to further discussion.</i></p> |
| <p>Repeating the question</p> | <p>When the patient does not seem to understand the question, misinterprets it, seems unable to make up his or her mind or strays from the subject, it is often useful to repeat the question. Hearing it for a second time may help the person answer; they may not have heard the question fully for the first time or missed the question’s emphasis.</p> |
| <p>Repeating the person’s reply (summarizing, restating)</p> | <p>Simply repeating what the other person has said in your own words, is often an excellent probe. Hearing his or her idea repeated often stimulates further thought by the person.</p> |

| Technique | How to Implement |
|--|--|
| <p>A neutral question or comment (clarifying questions or comments)</p> | <p>Neutral questions or comments are frequently used to obtain clearer and fuller responses.</p> <ul style="list-style-type: none"> • “Could you tell me more about your thinking on that?” • “I’m not sure I understand what you have in mind.” • “What do you think makes that so?” • “What do you think causes that?” • “Anything else?” <p><i>Note: This technique can arouse the patient’s desire to cooperate with a coach who is trying to do a good job. However, it should not be overplayed. The patient should not get the feeling that the coach doesn’t know when a question is properly answered or can’t understand. This approach is very useful in dealing with what appears to be an answer that is inconsistent with the previous answers.</i></p> |

HELPFUL RESOURCES

GRIEF AND LOSS

End Stage Renal Disease (ESRD) patients suffer immense losses as their disease progresses. Even those of us who have made a good adjustment to our new lives recognize that we have sustained losses. In fact, it is through grieving that we often come to terms with our new lives.

Some losses go by unnoticed because they are minor or seem unimportant to us at the time. Some losses are severe. These kinds of losses cut us off from someone or something that gives life meaning, purpose, safety, or predictability.

Losses are hard to bear and come in many shapes and forms. The loss may be tangible: a prized possession, a home, a job, the death of a friend or spouse. They may be symbolic, like the loss of a fond hope or statues.

Every loss is a very personal experience. Since no two people will experience a loss in exactly the same way, there are no formulas for how much a loss will hurt or how long it will last. Nevertheless, there is a natural and common response to loss that promotes healing and growth.

Here are some losses that common to almost all of us.

- 1. Strength**
- 2. Vitality**
- 3. Energy**
- 4. Control**
 - a. Time
 - i. We are now working with a dialysis schedule
 - ii. Doctor's appointments
 - iii. Transportation needs
 - b. Our future
 - i. None of us grew up thinking we wanted to be a dialysis patient
 - c. Bodily functions
 - i. We can't eat and drink as we would like
 - ii. We have cramping
 - iii. We are cold—or hot
- 5. Identity**
 - a. Whether you were the "the man" or the "nurturing caregiver" these roles have probably changed.
 - b. We may have lost our jobs, our careers, our hobbies or our recreational activities.

6. Relationships

- a. Some relationships and/or friendships do not survive the change in lifestyle.

Recognizing these losses and recognizing the stages of grief may help you coach people who are in this phase of their recovery. In addition, it is important to realize that losses continue throughout your life. It is a part of life for everyone; it is just somewhat more complicated for those with ESRD.

COMMON PATTERNS OF GRIEF

The natural healing response to loss is a process called grief. Grief is a natural part of the cycle of change. There are patterns, or themes, common to the grief/growth experience. These patterns are illustrated in the grief/growth cycle.

The patterns of grief seldom unfold in as orderly a fashion as the illustration suggests. We can think of them as patterns that are woven together in steps moving forward and backward. The patterns of grief continue to emerge until change, or progress, can be recognized.

| | |
|---|--|
| Initial Awareness | An initial awareness that the loss has occurred followed by a buffering or awareness, commonly referred to as shock and disbelief. |
| Self-Preservation and Protection | Coping strategies are used for self-protection so that the full impact of the loss can be limited until the person feels it is safe to continue the process. Examples of these safeguarding strategies are anger, avoidance, searching and bargaining. Shock is also a self-protection mechanism. |
| Full Impact | Anguish, awareness and despair occur when the full impact and meaning of the loss is experienced. These are usually periods of very intense longing and sorrow, which diminish with time. |
| Recovery | The individual experiences healing and gains perspective on the loss. The recovery period is also a time for reorganizing one's activities and routines so that life without the lost person can be resumed. |

STAGES OF ADJUSTMENT IN GRIEVING

Understanding grief and helping a person to express feelings of loss may be a part of your role as Coach. The psychological shock reaction to chronic illness has been described as a period of mourning comparable to that of bereavement.

The conditions underlying mourning are similar in both instances. From your own experience, you will be able to understand another's grief and therefore empathize in a way that many cannot.

Several grief models have been presented over the years. For example, Elizabeth Kubler-Ross identified five basic stages. The model outlined by Granger Westberg in his book *Good Grief* identified 10 stages. *For information on these models, see the Additional Resources section at the end of this manual.*

Each person responds to illness, including ESRD, in a highly individualized fashion. It is safe to say there are as many patterns of grief as there are people on earth. Some people will be in one stage for weeks, months or years. Some will be in two or three stages at one time. A stage might disappear completely, and then surface again later in the grieving process.

The important thing to remember is that when a person suffers a major loss or change, some form of grief is usually experienced, and many different reactions are normal.

A BASIC GRIEF MODEL



Shock

Shock is often but not always the first stage of grief. It usually follows injury, illness, or diagnosis or prognosis. Shock can last hours or days depending on the person's physical condition, environment, or mental status. Signs may include the following.

- Confusion
- Inability to express emotion
- Reduced responses

Denial

Denial is a defense mechanism in which the ego refuses to allow awareness of some aspect of reality. In this case, the aspect of reality is an ESRD diagnosis or prognosis. Most often the person who has ESRD, but it can be the spouse, parent, loved one, child of the person or other family members.

You may see a situation where the person is trying to deny his or her chronic illness, but a family member is saying "don't give up kid," "you're going to beat this thing," or "you've got what it takes." This puts a great deal of pressure on the person to perform. Perhaps it is something the person will never again be able to do. It can even create guilt in the person because he or she cannot do what a loved one desires.

If the person you are working with is in denial, consider the following.

- **Keep your cool.** You do not have to walk on eggshells, but do not argue about the person's situation. Encourage the individual to talk with others and get more information.
- **Provide gentle guidance.** You may try to orient the person to reality and/or guide him or her to accept the rehabilitation program or care.
- **Be patient.** People cannot usually be forced out of denial. They will be there as long as they need to be, sometimes to protect themselves from feelings they are not prepared to handle.

Bargaining

Psychologically, promises made with bargaining may be associated with guilt. A sensitive counselor or chaplain may wish to find out if the person is indeed feeling guilty from not attending church or if there are deeper unconscious hostile feelings that precipitate such guilt. Keep in mind, your role, as a coach is support, not therapy, if the occasion arises.

Some people bargain with their doctor.

- The quadriplegic might say, “Doctor, if I can only get the use of my hands back, I will be the best paraplegic the world has ever seen.”

Some people bargain with themselves.

- “Now, I am going to go to physical therapy and I will work hard. I’ll do my exercise every day and this way I’ll get well.”

Some people go to the top and bargain with God.

- They might ask, “Lord, let me have an illness instead of my child being ill.”

Bargaining is often an attempt to postpone reality. The following are some characteristics of bargaining.

- It has to include the price offered, e.g. good behavior.
- It sets a self-imposed deadline.
- It includes the promise that the person will not ask for more if this one postponement is granted.

Anger

Anger is a stage of grief that is not always evident. Sometimes it surfaces with other stages, and can last days or months. At its worst, anger can cause a person to prevent his or her own care and/or friendship.

Tolerating the person’s rational and irrational anger may be one of the caregiver’s most difficult responsibilities. We need to learn to listen and understand irrational anger. There can be real relief in expressing anger.

When dealing with another person’s anger, consider the following.

- **Try not to judge.** Look at the underlying dynamics rather than seeing only the behavior presented.
- **Recognize other people’s limits.** Some of us can deal with anger more effectively than others can.

Depression

People are sometimes difficult to help due to their feelings of hopelessness, lack of motivation and general apathy. These can be signs of depression. It is easy to withdraw from this type of person because their feelings of hopelessness may influence our own feelings.

These feelings serve little purpose but to reinforce a lack of self-esteem and sense of worthlessness. A major function as a Coach should be to counteract with the person's feelings of worthlessness or hopelessness with optimism.

Signs of depression:

- Changes in sleep patterns
- Changes in appetite, overeating or lack of appetite
- Cessation of or difficult menstruation in women
- Indifference to physical appearance—not getting dressed, poor hygiene, etc.
- Idleness
- Vague physical complaints
- Periodic weeping spells
- Desire to be alone or inactive
- Increased anxiety

By spending time with the person, we are saying we consider them worthwhile, even if we are just listening. Convey a caring attitude non-verbally by your ability to stay with them, to tolerate silence, to allow weeping, etc.

It is not our custom to touch or handle that which is worthless or useless, therefore, touch is often very effective. A willingness to extend oneself to another in desperate circumstances indicates concern and caring. Do not underestimate the effective of holding someone's hand while you are speaking to him or her.

Additional Types of Responses

Regression may also be seen in grief. It can range from immature judgments to actual childlike responses. For example, a person might lay in the fetal position for hours or even days.

A person may have lost a great deal of control that is associated with adulthood, such as when to eat, go to bed, and turn off the TV. Perhaps they have lost control of bowel and bladder function. Under these circumstances, they find their needs similar to those of a child.

Regression is sometimes called the "Why me(s)?"

- What did I do to deserve this?
- If only I had gone straight home.
- Why would God do this to me?

Fear: usually earlier in the grieving process, there is a stage of fear. The fear can be all encompassing and overwhelming.

- The person shows fear with just about everything.
- He or she may be afraid to turn in bed, to leave the window open, or have the lights turned off or to be alone.

Some will develop paradoxical reactions or do the opposite of what you expect for someone experiencing grief.

- They may do a lot of joking, finding great humor in their chronic illness.
- They may have loud, frequent bursts of laughter.
- They may show neurotic tendencies.
- They may be overly nice and polite.

Shame and **guilt** are also responses to grief. The person may feel that he or she has a physical disability and is being punished for some wrongdoing. The person may think “I was too drunk or stoned to be driving.” Or he or she may feel they’ve disgraced themselves and their family. Very often one is embarrassed at the diagnosis and feels now socially unacceptable.

Adaptation

The last stage of grief will often be **adaptation, or accommodation**.

- Some have discarded the word acceptance, because many chronically ill people felt it sounded like they liked or approved of their illness.
- The person, who has reached adaptation or accommodation, will reach a point when they view ESRD as an inconvenience.
- Some will look back and feel they have grown and learned from the experience.
- Some will actually find advantages.
- Some will have found a worthwhile life in spite of the body change

COMMON GRIEF REACTIONS

People often think of grief as an emotional experience. It is. Grief is also a physical, intellectual, social, and spiritual experience. It not only affects how a person feels, it affects behavior. Here are some common ways people react during grief.

| Physical Reactions | Behavioral Reactions | Emotional Reactions |
|---------------------------------|--|-------------------------|
| Deep sighing | Detached from surroundings | Numbness |
| Weakness and fatigue | Searching for what is lost | Hopelessness |
| Rapid heartbeat | Disoriented to time and place | Spiritual Connectedness |
| Increased blood pressure | Withdrawn from friends and activities | Confusion |
| Increase in activity | Forgetful | Helplessness |
| Increase in self-care | Blameful of others | Bitterness-Vengefulness |
| Muscular tension | Apathetic regarding activities or future | Euphoria |
| Sleep disturbances | Preoccupied | Yearning |
| Decreased resistance to illness | Crying | Peacefulness |
| Weight and appetite change | Seeking solitude | Sadness |
| Neglect of self | Finishing "unfinished business" | Despair |
| Spontaneity | Seeking and providing forgiveness | Anger |
| Increased sensory awareness | Unable to concentrate | Guilt |
| Decrease in activity | | Felling of being lost |

Rinse & Repeat: A New Stage of Grief for Chronic Illness⁸

BY RAIN DANCER ON MARCH 12, 2012

I've known about the five stages of grief as described by Elisabeth Kübler-Ross for many years now (**Denial, Anger, Bargaining, Depression and Acceptance**). When my father died, I watched myself go through the stages one by one. It was hard for me to accept that he could possibly be gone forever when I had just waved goodbye to him only a few hours before his death (**Denial**). I was mad at the medics for not getting there fast enough, mad at the doctors for not seeing there was a problem with his heart (**Anger**). Although I knew no amount of pleading would bring him back, I still promised to do things better if God would just make it all a mistake somehow (**Bargaining**). The **depression** lasted for years—even into the **acceptance** phase. Even 20 years after his death, I still have occasional bad days when I just wish I could see him and get a hug from him. He left a hole in my heart that can never be filled and yet as much as I miss him, I'll only go through the 5 stages of grief once for his death.

You might be wondering why I am talking about death and grieving. What does all this have to do with chronic illness? Well, the day we get diagnosed with a chronic or life threatening illness—whether it be rheumatoid arthritis, fibromyalgia, multiple sclerosis, cancer or any other disease—we start the exact same grieving process that we do when someone we love dies. I think most of us realize this—it's not a new theory or concept. We mourn the loss of our good health, our future life that we might not have or the people and activities that we might lose along the way. But I've come to the realization that when you live with a chronic illness, you don't just go through 5 stages of grief and then you're done. There is actually a sixth step for us ... I call it the "**Rinse & Repeat**" step. It's a little like shampooing your hair. Yes, you've already done it once before, but after a while you'll need to rinse it off and do it over again. Thankfully, with chronic illnesses, the "Rinse & Repeat" step doesn't happen nearly as often as washing your hair.

Here's how I see the steps of grief with chronic illness:

We start with **DENIAL**. Are you sure the tests are correct? Maybe we should run them again, just to be sure. Is it possible one of the medications I'm taking created a false positive? We grasp for straws, we ask for second opinions, we hope that we're the .01% that got the wrong test back or the lab work was somehow tainted. We might even reach further and ask whether that poppy seed bagel we had for breakfast could have had an effect on test results.

But when all those slim chances, second opinions and lost hope fail to change our diagnosis, we fight to hold back our **ANGER**. We're mad at ourselves. Should I have made better choices in my life? Maybe if I had eaten better or exercised more? We're mad at the world—what did I do to deserve this? Don't I have enough going on in my life now? How am I supposed to take care of my family, my husband or wife or even myself for that matter? We might get mad at our

⁸ Dancer, Rain. 2014. 'Rinse & Repeat. A New Stage Of Grief For Chronic Illness?'. Blog. *Dancing In The Rain*. <http://idanceintherain.com/2012/03/rinse-repeat-a-new-stage-of-grief-for-chronic-illness/>.

parents—after all THEY have the genes that can cause these diseases. Why did it have to be me and not someone else in the family? Then we get mad at ourselves again for wishing a disease on someone because we never want to wish ill upon others. But we are mad ... we're mad at our doctors, we're mad at ourselves and we're really pissed at the disease that has come into our lives and high-jacked our body for malicious purposes.

That anger may stay around for quite a while. And it may even roll over into the **BARGAINING** stage. But we eventually realize that our anger is only hurting ourselves, so we move forward a bit. We try to make deals with our bodies, God and the Universe around us. If I promise to eat healthy and exercise more, can you please take this away from me? I promise to find better ways to handle stress ... just please make this go away. The medicines make me sick, but I promise to take them all if you'll just show me the way to a cure. We think of everything we've ever done wrong and we try to find ways to make up for those mistakes—hoping that somehow, by the grace of God the diagnosis will disappear. Miracles happen and we hope that we can bargain our way into remission.

But as the time passes, we start to realize that the bargaining isn't working. The test results continue to show bad things happening in our bodies and we feel worse every day. The number of pill bottles on the nightstand increases exponentially ... and each passing day we start to lose hope. We eventually find ourselves deep in the dark depths of **DEPRESSION**. What point is there in moving forward in life if I'm just going to end up crippled, unable to take care of myself or worse? What's the point of getting out of bed—I feel awful and the world will continue to turn without my help. Sometimes we stop thinking all together ... we just move through our days with the weight of the world pressing down on us, making it impossible to smile or enjoy anything in life. We lay awake in bed at night thinking of all the bad things that could be coming our way. We worry about how we're going to take care of ourselves or our family. We start to turn inward, only to see more darkness, fear, worry and doubt. And we slide down deeper into the giant hole that is depression, losing touch with the things we love and care about. Everything seems hopeless and the world becomes a very dark place for us for a while. We may eventually be able to see a light again, but we're so lost in the dark that we're not sure how we're ever going to climb out of this pit of despair that we've fallen into.

Many of us move slowly into the **ACCEPTANCE** phase of living life with a chronic disease while we are still trying to find our way out of the pit of depression. There are good days where the sun shines through the curtain of darkness and we're able to laugh a little, enjoy time with friends and, just for a while, forget about the disease that is eating away at us. These days give us enough light to find those first few steps on a ladder that lead us back to the real world. But there are also bad days where the pain or sickness is overwhelming and we seem to fall back a ways, sometimes quietly indulging in our own little pity party. But the ladder is there for us now. We've seen it. It may be rickety and fragile, but it is there to help get us out of the pit whenever we need it now. We just have to remember to feel for it and be brave enough to take that first step, no matter how dark the world may be around us. As each day passes, we find our way out a little easier and for longer periods of time. But the acceptance of the disease ... it

is a clear and definitive part of our existence now. Unwavering, still unwelcome, but we accept it and we work at moving on with our lives.

If we had been dealing with the loss of a loved one, we would now be done with the stages of grief. Still missing the one who was lost to us, but essentially done with the process. However, today we're talking about chronic illness. And while we are moving forward in life and learning to live with the adversities that we are given ... we wait. We wait for a time when the sixth step, **RINSE & REPEAT**, comes barging into our lives and forces us to relive the 5 stages all over again.

You see, **RINSE & REPEAT is the stage where your illness has taken a sudden turn for the worse** and you literally have to "rinse" off everything you went through before with the last diagnosis or crisis event and "repeat" the process again—only this time for different circumstances. It could be caused by many things. For example, losing the ability to continue walking on your own and having to make the decision to use a wheelchair. Or becoming too sick and fatigued to work anymore, thereby having to abandon your career and instead move into full time disability. With each one of these events, we essentially are mourning the loss of a piece of ourselves—whether it be the mobility and freedom we used to have or the career and work persona that we worked so long and hard to build over the years.

It seems as though with chronic diseases, we are destined to go through the "Rinse & Repeat" stage over and over as part of our lives. But with each new step we learn new coping strategies. We remember our path out of the darkness from before and we add to our experience of being human. We learn to redefine ourselves so that we can find a place of peace and acceptance in our hearts and in our souls. And though we may always hope that THIS time is the last time that we'll find ourselves in the muddy waters of grief again for the same disease, we also know that if it isn't we *will* have enough strength and support built up in our lives to handle just one more cycle of "Rinse & Repeat."

HELPING OTHERS THROUGH GRIEF⁹

Most grieving people do not need professional help—they need a friend. Here are a number of ways you can be a friend to someone who is grieving.

- **Be There.** Grieving people need support and presence much more than advice. It is important to offer support over time.
- **Initiate and Anticipate.** Intensely grieving people often do not know or can't ask for what they need. Suggest times you would like to visit and ways you would like to help.
- **Listen.** Grieving people often need to tell their stories repeatedly. Listening without judgment or interruption can be the most important gift you give.
- **Avoid “Clichés” and Easy Answers.** “I’m sorry,” “I care” or “You’re in my thoughts and prayers” may be the best response. Touch can say in silence what words cannot express.
- **Silence is Golden.** Sometimes there are no words for grief and no words that bring enough comfort to take away the pain. Silence can demonstrate your trust and acceptance.
- **Accept and Encourage the Expression of Feelings.** Reassure the person that grief has many feelings and that feelings are like barometers that indicate our internal weather. Expressing feelings can help change the weather.
- **Offer opportunities and Safety for Remembering.** There are many times during grief that remembering helps the healing and growth process. Offer to revisit places and people who can add perspective and confirm the importance of the loss.
- **Help the Person Find Support and Encouragement.** Help the bereaved person find a variety of support and social activities.
- **Allow the Person to Grieve at His or Her Own Pace.** Grief is an individual process. Your ability to not judge the length of time it takes will lighten the pressure to conform others needs or ways and will enhance self-trust.
- **Be Patient ...** With yourself and your friend. You may need to give more of yourself than you imagined. Make sure you have some means of support and self-care to see you through.
- **Provide for Times of Lightheartedness.** Grief can be like swimming upstream—sometimes you need to get out of it and recoup. Laughter and diversions are wonderful ways to regain energy.
- **Believe in the Person’s Ability to Recover and Grow.** Your hope and faith may be needed when theirs fail. Your trust in the other’s ability to heal is essential. Listen and be with them in emotional pain. DON’T PUSH!

⁹ Helpguide.org,. 2014. 'Supporting A Grieving Person: Helping Others Through Grief, Loss, And Bereavement'. <http://www.helpguide.org/articles/grief-loss/supporting-a-grieving-person.htm>.

SEXUALITY, BODY IMAGE, AND CHRONIC KIDNEY DISEASE

Not everyone is comfortable talking about his or her sexuality. But the truth of the matter is that this silent concern plagues many ESRD patients and they are often reluctant to bring it up with their health team. Therefore, they may silently suffer with their sexual problems and dismiss this part of their lives as unimportant.

Similarly, not all coaches will be comfortable talking about sexual problems with their patients. If, however, you read the article presented in this section, you will find that the subject is just another part of ESRD and there are some simple solutions. You may choose to share these articles with you patients and suggest they take them to a member of their health team for further information.

Remember, you are not a doctor, a nurse, a social worker or a therapist. You cannot give medical advice to another person, and you should not invade his or her privacy. However, you can listen, provide information, and help address the issue through the problem solving steps you have already learned.

Sexuality and Chronic Kidney Disease

Over half of all people with chronic kidney disease experience some problem with sexual function. This can vary from just a lack of interest to a complete inability to reach orgasm. For many people, this can have a devastating effect on their self-esteem and put further stress on an already stressed intimate relationship.

Talking with one's partner or the healthcare team about sexuality, orgasm, or sexual problems may cause feelings of embarrassment. Because these topics sometimes make us feel uncomfortable, many people choose to ignore the problem. Whatever the cause or difficulty, sexual problems can often be corrected.

CAUSES OF SEXUAL PROBLEMS

Fatigue

Fatigue is a major factor. Any chronic illness is tiring, and chronic kidney disease, which is often accompanied by anemia and a demanding treatment, practically guarantees fatigue.

Depression

Depression is another common issue. Almost everyone experiences periods of depression, and one of the symptoms of depression is loss of interest in sexual intimacy.

Medications

Medications can also affect one's ability or desire to have intercourse. Since there may be other medications that are just as effective without the side effect of loss of sexual function or desire, talk to your doctor about your pills.

Feelings about body image

Having a peritoneal catheter, or a fistula or graft, may cause some people to avoid physical contact for fear of feeling less attractive or worrying about what people think when they look at them.

Diseases

Some diseases, such as vascular disease and diabetes, can lead to decreased blood flow in the genital area, decreased sexual desire, vaginal dryness, and impotence.

HOW TO GET HELP

- The most important thing is to feel comfortable discussing your problems. Talk to the member of your healthcare team with whom you feel most at ease—your doctor, social worker, nurse or pharmacist.
- The first step is a medical review to determine if the problem is physical.
- You may be referred to a social worker, psychologist, psychiatrist, nurse specialist or sexologist to look at non-medical factors. Assessment is often followed by counselling and education.
- Learning how to speak more openly with your partner is essential. By clearly expressing your personal needs, you can often reduce anxiety and improve your feelings about your sexuality.

For men

Common concerns may be erectile dysfunction (problems achieving or keeping an erection), reduced sexual desire (low libido), and ejaculation issues. Treatment options may include counselling, penile implant, male hormones, oral medications, or those that are injected. Ask your doctor for a referral to an erectile dysfunction specialist for a complete evaluation including a review of your medications.

For women

Women may also experience decreased libido. For those who have problems with vaginal dryness, a number of options are available: creams or devices that contain estrogen can be put into the vagina; lubricants can also be used. In addition, regular sexual stimulation in any form helps improve vaginal moisture. Talk to your partner about your needs.

Here are some things that may help change how you feel about yourself.

- **Take extra care with personal grooming.** When you look good, you feel good.
- **Try not to think of sexual intercourse as the only sex act.** This may cause you unnecessary distress if you have limited desire or energy. Sexuality doesn't have to include intercourse. Many forms of sexual expression don't require as much energy and are enjoyable such as hugging, kissing and caressing. Work with your partner to find enjoyable ways to give and receive pleasure.
- **If you are shy, books can be a good source of self-help.** Go to your local library or a bookstore and find a book that deals with your concerns. On the internet, you can search for useful websites and patient discussion boards about sexual functioning. It can be helpful to see that sexual concerns are common, and that help is available.
- **Don't ignore the problem.** Keep in mind that a positive attitude is an important part of good physical health.

***How does chronic kidney disease affect sexuality and intimacy?*¹⁰**

Dealing with the health problems caused by kidney failure can be difficult. It is easy to get caught up in the medical side and forget the enormous impact it also has on your personal life. One of the areas that is often overlooked is sexuality. This is a very personal topic and some people may not feel like talking about it.

Chronic kidney disease, as well as other health issues such as diabetes and high blood pressure, can affect your sex life.

Other medical issues, medicines and psychological factors can also have an impact. If you have a good relationship with your partner, it will probably be easier to work through these issues. However if you and your partner were having intimacy problems before you developed kidney failure, there is a chance that the effects of your condition may cause them to become more serious.

What is sexuality?

Sexuality is more than just sex. It is an important part of who you are, how you see yourself, how you express yourself, your sense of self-worth and your sexual feelings for others. Sexuality differs from person to person and is influenced by many factors, including religion, culture, age and individual situations.

Sexuality is expressed in many ways—the clothes you wear, the way you move, the way you have sex and who you have sex with. It also affects how you feel about your body and how you look (body image).

How do physical changes affect your sexuality?

Kidney failure brings many physical changes that can affect how you feel about your body and your sexuality. Some of these physical changes can be

- body odor
- bruising
- decreased endurance and energy levels
- extra fluid from fluid retention or carrying peritoneal dialysis fluid
- hair loss or gain
- bad breath or a 'coated' tongue
- reduced ability or inability to reach orgasm
- skin changes such as itchiness, dryness or color
- strength and control
- weight changes

¹⁰ Kidney.org.au,. 2014. 'Sexuality'.
<http://www.kidney.org.au/ForPatients/Management/Sexuality/tabid/822/Default.aspx>.

Don't be afraid to **talk to your doctor about these changes** as some of these changes can be treated or managed in a way that can make you feel better about your body.

How does kidney failure affect physical sexual intimacy?

You may be faced with tiredness, decreased sexual desire; reduced ability to orgasm, changing body features and be on constant medication. This can often mean that sex, or even the idea of sex, is the last thing on your mind. However, most people, particularly if you have previously enjoyed a good sex-life, at some stage like to restart sexual intercourse.

The physical side effects of kidney failure may affect your ability to perform sexually. It is important that partners are aware of these side effects and understand they are not anyone's fault. You may experience, one or more, or perhaps none, of these side effects:

Ability to orgasm—less energy, hormone changes, hardening of the arteries in the pelvis and blood pressure medication all make it harder to climax. This may be solved with a change in blood pressure medication, extra hormones or more foreplay.

Arousal—the buildup of waste in the blood, tiredness, loss of sexual desire and emotional state may also affect your sexual arousal and it may take longer to be 'turned on.' Partners may need to explore foreplay, spending more time pleasuring each other, with or without intercourse.

Dry vagina—lower hormone levels and the effect of some medications for women may lead to a dry vagina, which can cause pain during intercourse. Uncomfortable or painful intercourse can affect the desire to have sex. A water-soluble vaginal lubricant can be helpful. Oil-based jelly is not usually advised as it increases the risk of infection and may damage some contraceptive devices such as condoms.

Emotions—if you are depressed, anxious or worried about your health, you will probably be less concerned or interested in sex. You may find that once you have adjusted to dialysis that your health improves and your sex drive increases. Despite feeling better, some people still experience sexual problems caused by emotional factors.

After a transplant—feelings that may add to sexual problems can include fear of sexual failure or anxiety about damaging catheters and fistulas. Some people worry about changes to their appearance. A change in body image may not affect your ability to have sex but it may make you feel less sexual.

Does Chronic Kidney Disease cause impotence?

Men often report some degree of impotence—even those without kidney failure. Impotence, also called erectile dysfunction, is when a man's penis does not become hard, reducing his ability to have or maintain an erection to the point where he is unable to have sexual activity with penetration.

The physical and emotional effects of kidney failure can affect getting and maintaining an erection. These may include:

- changes in hormone levels
- buildup of waste and fluid in the blood
- problems with blood circulation
- nerve damage
- anemia
- low vitamin and trace metal levels, e.g. zinc
- reduced strength and energy levels
- medication, particularly blood pressure tablets
- low self esteem
- body image problems
- depression, anxiety and stress
- fear of being unable to perform sexually

Worrying about it often makes it worse.

For many men who have or have had problems with impotence, the fear and negative thoughts about being unable to get or keep an erection can create erection anxiety.

As with all medical problems, the best treatment really depends on the cause of the problem and personal preferences.

It is important that you talk to someone who knows your health history and understands the medications that you are taking. Treatment for erectile dysfunction is available in a number of forms. Most people start off with tablets.

Medications have been shown to be safe for people with kidney failure, though people with some heart conditions and on certain medications should not take them. It is best to talk to your doctor about these medications and other ways of managing impotence.

How do I talk about sex with my partner?

It is important to remember that most couples experience some problems with sex and intimacy. No couple has a perfect sexual experience every time. It is just a matter of working out what is best for you and your partner.

Communication is important for a successful, sexual relationship

You need to talk to your partner about what is happening to you sexually, physically and emotionally. Sex is something that you and your partner share together so it is important that you find answers together. Talking about sex can be difficult. Following are some hints to make it easier:

- think through what you want to say before you say it
- choose a time when you are both relaxed and can concentrate. Make sure you do not discuss it during an argument or after a frustrating day.
- choose a place where you and your partner feel comfortable. Sex is a personal subject and your partner may not feel comfortable discussing it in a public place.
- make sure that your conversation does not begin with excuses or blaming.
- allow your partner to share feelings and really listen to what they are saying—remember that your partner is not a mind reader; avoid upsetting each other with second guesses as to what you like and how you are feeling.

For those couples having difficulties discussing sex and intimacy, there are many organizations that have counsellors that specialize in sexuality and relationships. Talking to a counsellor may help you and your partner to learn how to communicate about sex and intimacy and explore ways of satisfying each other. You may want to talk to your doctor or another health professional about getting a referral to a counsellor that specializes in these issues.

What can I DO to maintain my relationship?

All relationships require time, effort and understanding to make them work. This can become much harder if you have a chronic condition. Not only are you dealing with the usual relationship ups and downs but also the added stress of chronic illness.

Sex and intimacy are more than just intercourse

There are many other ways to express intimacy and satisfy both yourself and your partner. Through simple gestures and touching you can still express the feelings of desire, closeness, love and affection that you have for each other. Here are some other suggestions:

- make time for one another
- attend appointments together
- stay informed
- give your partner time out from treatment
- get professional help
- maintain your own interests

There is no secret to maintaining a happy relationship when one partner has kidney failure. The best you can do is be honest with one another and supportive of each other's needs. While this is not always easy, having respect and trust means you are more likely to ride out the tough times as well as enjoy the good. Everyone's experiences are different. Remember there is no right way to feel when you are dealing with change. Accepting and talking about these feelings is one of the best ways of dealing with them and beginning to move on.

How do I balance a new relationship and a chronic disease?

Meeting a potential new partner can be an exciting but sometimes nervous experience. It is hard for everyone but having a chronic condition can make it even harder. Concerns about yourself may surface and make you feel less desirable. You may be dealing with lifestyle

changes e.g. dietary restrictions or dialysis demands, anxiety due to sexual problems, body changes such as fistulas or catheters and weight changes. Be aware, however, that we are often more critical of ourselves than others around us.

Before entering a new relationship you may want to consider whether you have the energy and time to give to a new partner, particularly if you are not feeling well. If you are wanting to meet someone new, you may need to think about how to explain chronic kidney disease, its effect on you and how it is likely to affect a new partner.

Telling a partner or potential partner about sexual or fertility problems can be very difficult as this is a highly sensitive and personal area. It is important that you are up-front with your potential partner, as they will find out anyway. If the person really cares about you, then it may not matter to them that you are experiencing troubles with your sexuality.

END OF LIFE DECISIONS

Not everyone will be comfortable coaching those patients and/or family members who are making End of Life Decisions. However, at some point in your Coaching career, you may be faced with someone who is making these decisions. Reading this section is important so that you will know how to respond if the topic is raised even if you choose not to coach on the subject. An understanding of the protocols involved may open up this subject for your consideration. Working with those who are facing these decisions can be very rewarding.

One observation for your consideration is that patients who are making the decision to withdraw from dialysis, if not reacting out of depression, have made a considered decision based on their personal value system and are comfortable with the decision. They have worked with their social worker, their physician and/or a psychologist to make sure that they have made an informed choice and they are very secure in their decision.

Family members of patients may not feel ready to “give up the fight.” You may spend more time coaching reluctant family members than the patient who is ready to let go. In these situations, use your empathic listening and knowledge of grief to assist the family in accepting their loved one’s decision. Perhaps pointing out the differing value systems they are working with will help them to understand the decision that they are having trouble accepting.

WITHDRAWAL OF DIALYSIS

When an individual with renal, or other organ failure, decides to withdraw from dialysis or other medical treatments they will die within a short time. The decision to withdraw from treatment is one that a person must make carefully and after much discussion.

If the patient should raise the subject, the coach should bring this issue to the attention of the social worker by using the protocols outlined in the section of this manual on confidentiality.

As a coach, you should let the patient know that you are concerned about what they are saying. Encourage them to discuss it with someone: their family, doctor, social worker, or nurse. If they refuse, let them know that you are worried about them and that this is an instance that you cannot keep confidential. **Let them know what you are going to share, who you will share it with and why.**

The decision to withdraw treatment should reflect the patient's values and wishes. Withdrawal from treatment is a complex decision that may be based on religious and social views, as well as other factors unique to each individual.

There are no specific criteria to determine which person might wish to withdraw from treatment. Age and physical disability should not be used as criteria for encouraging withdrawal from treatment. In addition, it is critical that the patient's decision to discontinue treatment is not the result of transient depression or sadness from recent medical or personal setbacks.



SUICIDE AND HOMICIDE

If a person asks questions about or expresses any thoughts about ending their own life, or indicates that they are very sad and/or depressed, the Coach must consider that this person has an increased risk of suicide. Some of the important indicators of depression are explained in the section of this manual on depression.

The Coach must alert the social worker or unit immediately of any person who has expressed any wish to end his or her own life, or has demonstrated any signs of significant depression. This communication should be made before the patient leaves the facility, so that the medical team/caregivers can determine if emergency medical and psychological intervention is required.

If a person indicates to a coach that he or she has any knowledge of or involvement in a homicide or planned homicide, the coach is required by law to provide this information to the appropriate legal authorities. The courts have ruled that this information is not protected by patient confidentiality. The social worker or clinic nurse can assist the Coach in contacting the legal authorities. It is of urgent importance to transmit this information to police authorities if the homicide is planned but was not yet completed.

SERVING AS A COACH



ARRANGING APPOINTMENTS

SETTING UP THE FIRST APPOINTMENT

1. Make personal contact (telephone) prior to the first meeting
2. Introduce yourself as a coach
3. Acknowledge the referral person
4. Ask how they are doing.
5. Express your willingness to meet.
6. Reaffirm the person's interest in meeting.
7. Confirm date, approximate length of appointment, who's attending and an agreeable location.
8. Check to see if any special pre-arrangements need to be made (if at a hospital or dialysis facility.)

FIRST MEETINGS

First Meeting with Person/Saying Hello and Describing Your Role

1. Reintroduce yourself and show Coach identification card if your unit provides them.
2. Briefly explain your role to provide appropriate information and emotional support to patients and families using both your knowledge of coping skills and person experience. In short, I've been there too, so let's talk.
3. Talk about the confidentiality of the meeting.
4. Mention the patient log you will be completing and forwarding to the referral person if it is required element of your unit. .
5. Reaffirm the person's interest in meeting.
6. As an ice-breaker (if needed), you may wish to share briefly how you "wish you had or were fortunate enough to have someone to talk with who had been through this."
7. Allow the person to establish content of learning. Don't push.
8. Normalize their anxiety/ambivalence
9. Listen—let the people tell their stories.
10. Remain objective and semi-professional.
11. Ask if the person would like to make another appointment.
12. Complete Coaching Log and return promptly if your unit requires it.

ESTABLISHING RELATIONSHIPS

- Accept personal responsibility for your own well-being.
- Don't take things personally—there are no failures.
- Respect the individuality of the person. If you cannot relate or work with the referral, be honest, talk to your facilitator.
- Stick to your Coach role.
- **Never offer financial assistance.**
- If in doubt, don't do it. Check with facilitator.
- Review manual as often as needed for reference.
- Never do for others what they can do for themselves.
- It's okay to say "I don't know." Follow up with "Let's find out."
- Be aware you are a participant and an observer in the relationship.
- Be alert to not only to the person's behavior, but also your own reactions and behavior.
- Keep in mind the primary task is helping people.
- You will be affected by a patient's death. Talk with your Social Worker.
- Allow people to express their negative feelings without taking them on

DISCONTINUING RELATIONSHIPS

- Separation is the natural phase for this type of relationship.
- All relationships have periods of ups and downs. A down period does not necessarily mean it's time to separate.
- The relationship is patient-directed. Through active listening, you will be able to “hear” cues from the patient regarding his or her need for maintaining or separating the relationship.
- If you listen, you will hear the patient confronting his or her own autonomy and independence. Look for indications that the relationship has changed (the roles of Coach and Patient become more equalized.)
- When a patient is ready to separate, it really means you have done your job.
- Bear in mind that it is sometimes difficult for the Coach to separate.

ADDITIONAL RESOURCES

Benefits of Coaching Programs

Learn more about the NKF's Peer Support program by visiting:

www.kidney.org/professionals/Peers/pdf/02-10-4196_EBB_BenefitsProfessionalFlyer.pdf

Helping Others Deal with Grief

Elisabeth Kübler-Ross Foundation,. 2014. 'Elisabeth Kübler-Ross Foundation -'.

<http://www.ekrfoundation.org>.

Westberg, Granger E. 1971. *Good Grief*. Philadelphia: Fortress Press.

Withdrawal from Dialysis

Kidney.org,. 2014. 'Dialysis: Deciding To Stop | The National Kidney Foundation'.

<https://www.kidney.org/atoz/content/dialysisstop>.

REFERENCES

- B, Zoe. 2014. '6 Ways To Enhance Your Productivity'. Blog. *Lifhack*. Accessed November 18.
<http://www.lifhack.org/articles/productivity/6-ways-to-enhance-your-problem-solving-skills.html>.
- Covey, Steven. 2014. 'Setting Your Life Priorities Right'. Blog. *Coaching-Journeys.Com*.
<http://coaching-journey.com/2013/02/setting-your-life-priorities-right/>.
- Dancer, Rain. 2014. 'Rinse & Repeat. A New Stage Of Grief For Chronic Illness?'. Blog. *Dancing In The Rain*. <http://idanceintherain.com/2012/03/rinse-repeat-a-new-stage-of-grief-for-chronic-illness/>.
- Deveraux, Ronda. 2013. 'Setting Your Life Priorities'. Blog. *Choice Life Strategies*.
<http://choicelifestrategies.com/setting-your-life-priorities/>.
- Helpguide.org,. 2014. 'Supporting A Grieving Person: Helping Others Through Grief, Loss, And Bereavement'. <http://www.helpguide.org/articles/grief-loss/supporting-a-grieving-person.htm>.
- Iscoe, Louise, and Karen Bordelon. 1985. 'Pilot Parents: Peer Support For Parents Of Handicapped Children'. *Children's Health Care* 14 (2): 103-109.
 doi:10.1207/s15326888chc1402_6.
- Kidney.org.au,. 2014. 'Sexuality'.
<http://www.kidney.org.au/ForPatients/Management/Sexuality/tabid/822/Default.aspx>.
- Mayoclinic.org,. 2014. 'Being Assertive: Reduce Stress, Communicate Better - Mayo Clinic'.
<http://www.mayoclinic.org/healthy-living/stress-management/in-depth/assertive/art-20044644>.
- Peavy, Vance. 1977. *Empathic Listening Workbook*. [Victoria, B.C.: Adult Counselling Project,

University of Victoria.