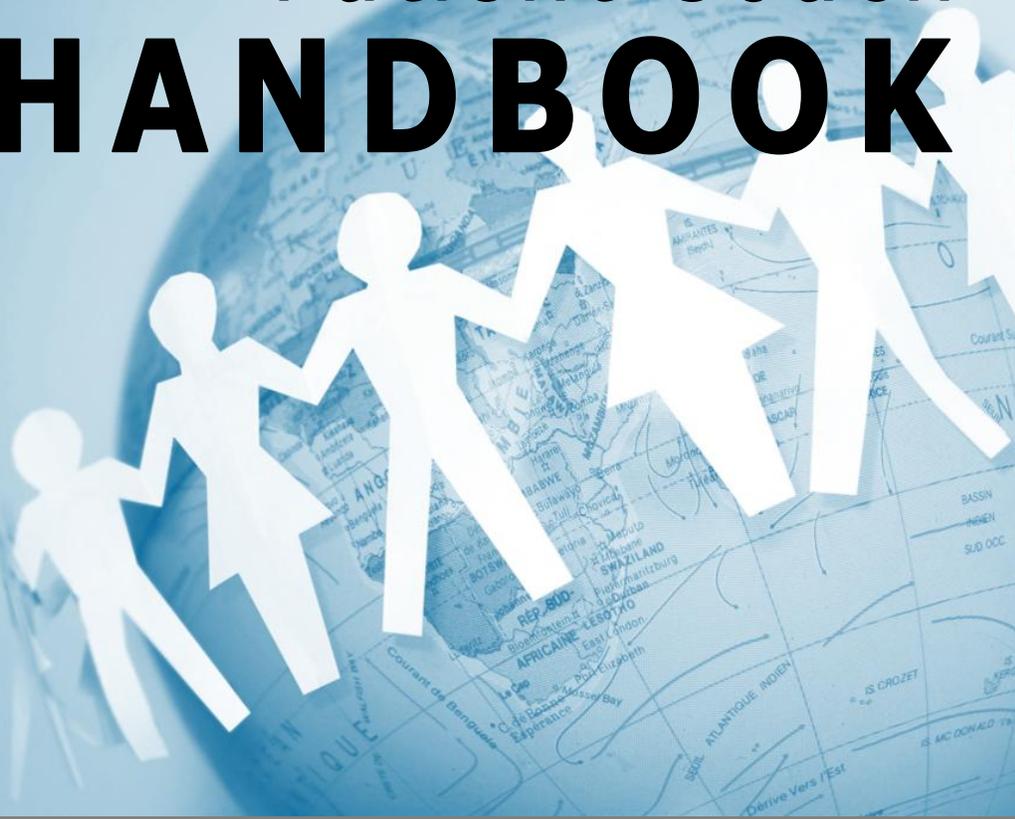




Patient Coach **HANDBOOK**



**Fistula
Coaching
Program**

FORWARD

As the saying goes:

“YOU DON’T KNOW ‘TIL YOU’VE BEEN THERE.”

There’s a lot of truth in that often used statement.

As someone who has experienced a fistula, you have something unique to offer other patients that no staff member can.

Your fellow patients who do not have a fistula need someone or something to motivate them to take action for change. You and your experience with a fistula may well be that “someone or something” for one of your fellow patients.

You represent living proof that life can still be good to a person who has a fistula.

This guidebook is here to help you with the important task of sharing that information.

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INTRODUCTION

The Fistula Coaching Program is designed to promote the best vascular access choice among patients through peer-to-peer education, communication, planning and problem solving. The program is provided through a trained, facility-based, patient volunteer program called the Fistula Patient Coach.

For the purposes of this document, patient volunteers in this program will be referred to as a “patient coaches” or “coaches.”

The role of the patient coach is vital to the Chronic Kidney Disease (CKD) patient contemplating the arteriovenous fistula and wanting to know more about this vascular access option from someone who has been there.

An arteriovenous fistula is also known as an AV fistula, an AVF or a fistula.

This handbook has been developed to support the work of the Fistula Patient Coach. Our intention is to better guide the work of new program volunteers as well as to provide the veteran patient coach with some ideas for program enhancement. These materials can be adapted, as needed, to meet the needs of your facility.

As you work to improve education and support for patients through this program, please remember that the work you do is important to both the individual patient as well as the larger facility patient community. Thank you for becoming a part of the Fistula Coaching Program team.

A Brief Word about the Change Process

Research shows that change is usually a process. This means that you may need to visit the patient a number of times in the “process of change.”

It is important for patient coaches to develop a relationship with the patient needing assistance and to gradually build up trust so you can be of assistance in the process of change.

Relationships need to be based on respect and acceptance of the patient’s right to self-choice.

You will need to listen and ask non-threatening questions that will help you understand the patient’s viewpoint.

As a patient coach, your aim is to help identify and eliminate the obstacles that are holding the patient back from making a choice.

In the end, the patient makes the decision on whether or not to proceed with fistula placement based upon their belief that it will or will not help him/her meet personal needs or goals.

I. THE FISTULA PATIENT COACH

A. Is a Support Person For:

- A newly diagnosed person with Chronic Kidney Disease (CKD), Stage IV or V approaching dialysis and has chosen hemodialysis.
- A CKD patient who has already been on hemodialysis, but does not have a fistula and is interested in learning more.

B. Is a Hemodialysis Patient Who:

- Copes well with kidney failure
- Has a working fistula
- Understands how to care for a fistula
- Wants to share this experience and knowledge to help fellow patients improve their quality of life
- Has good listening and communication skills

C. Is Expected To:

- Visit the patient
- Provide appropriate resources
- Help with problem solving
- Encourage the patient to talk to his or her doctor, to a vascular surgeon, and the health care team about fistula concerns
- Provide emotional support for whatever decision the patient makes regarding fistula placement

D. Is Expected NOT To:

- Offer personal opinions or advise (especially give medical advice)
- Gossip about the unit staff, another patient, or patient family member

As a Fistula Patient Coach, you may receive training from the facility on appropriate and inappropriate behavior.

II. IDENTIFYING BARRIERS AND PROBLEMS

Help the patient to find his/her own answers to problems. Remember that helping is not solving problems for others; rather, it is a way to help someone use his/her own resources to solve these problems.

If a patient agrees that the fistula is to his/her advantage, listen to the patient regarding what problems he/she has regarding fistula placement. It really does not matter if you do not believe the concerns are true problems. If the patient sees it as a problem, then it is a problem.

- What does the patient see as the problem or stumbling block to getting a fistula?
- What does the patient think he/she needs to make an informed decision about getting a fistula?
- What help does the patient want from his/her doctor, health care team, and/or from you that will help him/her make the decision about the fistula?

III. BRAINSTORMING AND PROBLEM-SOLVING

Brainstorming is a process used by either a person or a group to list all ideas that come to mind about a specific topic.

- There is no right or wrong answer.
- List whatever comes to mind and list as many potential solutions as possible.
- Review the list and eliminate the ideas that are humanly impossible or just wishful thinking such as, “Find a crystal ball that tells me if an AVF is my best access option!”
- Provide more details about the ideas that can be carried out such as, gather information or talk to people who have a fistula.
- List the potential solutions in order of importance.
- Agree to try one solution.
- Evaluate if the solution was helpful and if it addressed the concern.

To record or develop solution statements use the “Problem–Solving and Brainstorming Worksheet” found in the Tools Section of this handbook.

IV. BASIC PRACTICES FOR A FISTULA PATIENT COACH

A. Respect For Patient Choices

a) When a Patient is interested in a Fistula Placement

- If the patient seems interested in learning more about fistula placement, give the patient some fistula-related resources.
- Share your personal experience of how a fistula has been a positive choice in your life.
- If the patient is ready, encourage him/her to make an appointment with a vascular surgeon.
- Reassure the patient that usually the benefits of the fistula outweigh the disadvantages in the long run.

b) When a Patient is undecided about a Fistula Placement

- Encourage the patient to write down the pros and cons of getting a fistula and to share his/her list with your Fistula Coaching Program Coordinator. Or, you can offer to give the list to your program coordinator if the patient prefers you to do it.
- Reassure the patient that it is typical to feel fear, anger, and frustration when there are decisions to be made regarding treatment options.
- Encourage the patient to write down medical questions that need to be answered by the nurse or doctor.

c) When a Patient is against a Fistula Placement

- Listen and be supportive of the patient if he/she needs to vent his anger and frustration at being on dialysis.
- Try to understand the patient's concern about getting a fistula.
- Listen to the patient who shares his/her fears and concerns about needles and having another surgery.
- If the patient is against getting a fistula, you can provide educational resources and encourage the patient to talk to the staff about his/her concerns.
- Listen to the patient who is strongly against learning about fistula placement. Be available when he/she wants to ask any questions about it at a later time.

d) When a Decision is made NOT to get a Fistula

- The patient who chooses not to have a fistula still needs to be accepted for the choice he/she made.
- Accept that it is not the right time for him/her to proceed with fistula placement.
- Be available to talk to the patient more in the future if the situation changes.
- You are not at fault if the patient decides not to see a vascular access surgeon.
- You have not failed in your activities as a Fistula Patient Coach if the patient has no interest in fistula placement after you meet.

Overall Practices

- Always be supportive of the patient and NEVER preach or tell the patient how he/she should feel or what he/she should do.
- Set limits for yourself and know that you can only do so much.
- Go at the patient's pace. People take in information at different rates and there are a number of factors that are involved in making decisions.
- Share your personal experience as needed.

B. Maintaining Privacy and Confidentiality

Patients participating in *The Fistula Coaching Program* have a right to privacy and confidentiality.

a) Privacy

As a patient coach, you may not ask about concerns that do not relate to the Fistula Coaching Program. As a patient coach, you can prompt or encourage patients to speak about something related to fistulas but it is the patient's choice as to how much to say. If the patient brings up a concern that does not relate to the Fistula Coaching Program, please be sure to include this in your visit notes and let the program coordinator know.

b) Confidentiality

The patient has trusted you, in private, with his/her thoughts, feelings, and concerns. Even if the patient chooses to openly discuss the same concerns with others, as a Fistula Patient Coach you are still required to keep your discussions private.

It is very important NOT to talk to either your family or friends about the patients with whom you visit. Even if family members and friends do not know the patients, it is not okay to talk about them or what they say to you.

The only exception is that you may talk to your Fistula Coaching Program Coordinator about your visits. Also, if you have concerns about the safety of a patient, report these concerns immediately to your Fistula Coaching Program Coordinator. If this person is not available in an emergency situation, talk to the program alternate, nurse manager or social worker.

Your Fistula Coaching Program Coordinator may ask you to sign a *Confidentiality Statement*. This is basically a written promise that you make to respect what is said to you by patients during patient-to-patient coach visits.

C. Practice Good Communication Skills

Good communication is a skill even when chatting with others informally. The following techniques have been developed over time to assist individuals in the development of appropriate interaction:

a) Establish a Connection

When people find others they believe are “like” them, they feel a connection.

- Introduce yourself and ask the patient what name you should use to address him/her, for example, using a first name, a nickname or more formally as Mr., Mrs. or Ms.
- Identify yourself as a fistula user.
- If the patient is nervous about talking to you, help the patient feel more at ease by first talking about more casual subjects such as hobbies, sports, community or current events. Finding similar interests will help create the bond between coach and patient needed for one-on-one sharing of experiences.

b) Focus on the Patient

Peer education and problem solving require a collaborative effort. Understanding the patient’s point of view will help you to know how to coach him/her through the necessary steps of decision making.

- Be attentive.
- Listen without interrupting.
- Ask questions if you do not understand what has been said.

c) Non-verbal Cues

- When meeting with the patient, maintain the same eye level for example, stand if he/she is standing or sit if he/she is sitting.
- Always face the patient.
- Look at the person when he/she is talking and listening.
- Use appropriate eye contact; do not stare.

- Establish and maintain a comfortable distance. Being too close may feel uncomfortable while being too far away may seem standoffish. Be aware of gender and cultural differences.
- Use facial expressions (e.g. smiling), gestures (e.g. nodding your head) and body movement (e.g. leaning forwards) to let the patient know that you are listening and interested in what is being said.

d) Verbal Cues

- Speak clearly and loud enough to be heard without strain.
- Pronounce your words distinctly.
- Keep your language simple.
- Make only one point at a time.
- Avoid jargon, especially with new patients.
- Be sure that your verbal and non-verbal cues are giving the same message.

e) Other Communication Issues

- Understand that being quiet together is okay.
- Know that it is okay to say, “I do not know, but I will try to find out.” Or “I do not know, but I will try to find a resource for you.”
- Answer questions honestly and offer to have staff talk to the patient about specific questions that you, the patient coach, cannot answer.
- Assure the patient that your conversations are confidential and that you will not share what you are told without permission, except to your program coordinator.
- Explain that you will need to tell your program coordinator (or someone in authority) if the patient is being abused or talking about personal harm to himself/herself or others.
- Share your own experiences, if appropriate, but do not take over the conversation. Do not interrupt!
- Be certain to ask the Fistula Coaching Program Coordinator if the person has any hearing or visual problems or any disabilities that might hinder your communications and adjust your approach to address those issues.

Compensate for Visual Problems

- ◆ Identify yourself by name whenever you meet.
- ◆ If you share your phone number, write it in large dark letters.
- ◆ If you share reading material or other resources, try to do so in a well-lit location, without a glare, and have large print copies available or tape recorded information.
- ◆ Do not raise your voice if a person is having difficulty seeing you – only if there is also a hearing problem.

Compensate for Hearing Loss

- ◆ Check which side is the “good” ear and face the patient so that he/she can watch your lips as you talk.
- ◆ You may want to carry paper and a pen (or a magic marker) with you in case you need to communicate by the “written word” instead of the “spoken word.”
- ◆ Lower the pitch of your voice if the person asks you to repeat yourself and try to patiently repeat the information as needed.

- Ask open-ended questions to gather more information and to learn about the patient’s feelings.
 - ◆ What are your concerns?
 - ◆ How are you making your decision?
- Ask close-ended questions to gather basic information. These questions can be answered with a Yes or No.
 - ◆ Have you had a fistula before?
 - ◆ Are you scared of needles?

- Reflect, what you heard, back to the patient.
 - ◆ What I hear you saying is...
 - ◆ Do I understand correctly that you feel...?

- Clarify the problem.
 - ◆ It seems that you are unsure if the fistula will work well for you.
 - ◆ You hate the idea of changing something that seems to be working well at the moment.

V. TIPS FOR PATIENT-TO-PATIENT COACH VISITS

- All patients you visit must be recommended to the program by staff using the appropriate channels set up by your facility.
- All visits should be prearranged.
- Check with the patient to determine if he/she prefers to meet at the facility, during dialysis, at another location or by phone.
- Keep agreed upon times for visits or let the patient or your Fistula Coaching Program Coordinator know if you are ill or something unexpected prevents you from keeping the appointment.
- Before beginning your visit, check if it is still a good time to get together, even though the visit is prearranged. The patient may not feel well, may be in a bad mood, may be anxious or irritated, or may not want to meet at the specified time.
- Keep the length of your visits reasonable. A half-hour visit is usually appropriate. Take cues from the patient to decide if it is too long. If you need more time, schedule a longer visit for the next time.
- Meet with the patient as many times as he/she desires which may involve one visit or several.
- Thank the person for allowing you the privilege of visiting.
- Follow through on any commitments you make to the patient. If you say you will share a specific resource, call, or visit again, keep your word or inform the person if you are unable to do so.
- If you are not able to continue to visit a patient for any reason, let the patient and Fistula Coaching Program Coordinator know.
- Wear a name badge so patients and staff will know you are a Fistula Patient Coach. (Name badges are recommended but it is up to the individual units whether to use or not use name badges.)

Use the “Record Form” in the Tools Section of this handbook to document each visit.

VI. THE FISTULA COACHING PROGRAM COORDINATOR

The Fistula Coaching Program requires that a facility staff person, usually the Vascular Access Coordinator or the facility Social Worker, oversees and coordinates the activities of the patient coaches. Program coordinators are responsible for training patient coaches and for making sure that patient coaches are following facility policies and procedures. You will receive your program assignments from your Fistula Coaching Program Coordinator and you will need to report to the program coordinator on a regular basis.

You are a volunteer and although it is helpful to commit to your volunteer activities for a specific period of time, you may choose at any time to stop your volunteer work. However, it is helpful to talk to your program coordinator about it ahead of time and give at least two weeks' notice.

The Fistula Coaching Program Coordinator:

- Provides training on the facility policies and procedures
- Determines which patients you can visit
- Sets up the first visit for you or provides you with a way to set it up
- Determines how often to meet with you to discuss your volunteer work
- Provides guidelines for documentation of your visits with patients
- Suggests what materials to share with patients
- Is your resource person
- Answers your questions
- Responds to your concerns

Use the "Information Sheet" in the Tools Section of this handbook to record program coordinator contact information.

VII. TOOLS

The following are sample program materials. Each program may use “as is” or make changes as needed or simply create their own.

Information Sheet – record contact information for program staff

Record Form - record notes of your patient-to-patient coach visits

Problem–Solving and Brainstorming Worksheet - form to record and facilitate problem-solving and brainstorming outcomes

Information Sheet

Please write your Fistula Coaching Program Coordinator's name and telephone number below for easy reference.

NAME _____

FACILITY PHONE NUMBER
& EXTENSION (if one available) _____

Alternate staff to contact if Program Coordinator is not available:

First Alternate NAME _____

FACILITY PHONE NUMBER
& EXTENSION (if one available) _____

Second Alternate NAME _____

FACILITY PHONE NUMBER
& EXTENSION (if one available) _____

Problem–Solving and Brainstorming Worksheet

Identify the problem(s)

Potential Solutions (Be Creative!)

Choose which solution to do first

Decide when to check if the solution is working:

One Week One Month Two months Other: _____

If needed, what would the next step be?

VIII. RESOURCES

A. People

Your unit may have a Vascular Access Coordinator, a nurse or a social worker who will be your primary contact for your questions and those of the patient with whom you visit.

If you meet with a patient during a dialysis treatment, the nurse and/or dialysis technician providing care may be able to answer the patient's individualized questions about vascular access.

Most units have a Fistula First Quality Improvement Team made up of several staff members focused on fistula placement. These team members may welcome your input and may share their own goals, action plans and progress with you.

B. Network Publications

a) Brochures

- Ease the Ouch
<http://www.kidneypatientnews.org/resources/resources/EaseTheOuch.pdf>
- How Do I Look?
<http://www.kidneypatientnews.org/resources/resources/HowDoILook.pdf>
- Access Care – Your Lifeline
http://www.kidneypatientnews.org/resources/resources/access_booklet2000.pdf
- Arterial Venous Fistula (AVF) - Overview
- Renal Outreach Articles (The Renal Network Patient Newsletter)
 - ◆ Fall 2002 – One-Site-It is: http://www.kidneypatientnews.org/images/RO13_3.pdf
 - ◆ Summer 2004 – Vascular Access – Making Your Lifeline Choice:
http://www.kidneypatientnews.org/images/RO14_3.pdf
 - ◆ Spring 2006 – Frequently Asked Questions about Arterial Venous Fistula's (AVF): http://www.kidneypatientnews.org/images/RO16_1.pdf
 - ◆ Winter 2007 – The Naked Arm:
http://www.kidneypatientnews.org/images/RO16_3.pdf

b) Multi-Media

- Vascular Access: Dialysis Patients and Renal Professionals Speak About Vascular Access and the Vital Role it Plays in Hemodialysis Quality of Life (Network 9/10 DVD)
- Kidney Talk feature “Choosing and Caring for Your Vascular Access” originally aired on July 11, 2006 <http://www.rsnhope.org/domains/kidneytalk/shows/2006-07-11/index.php>

c) Web Sites

- The Renal Network, Inc: www.therenalnetwork.org
- Kidney Patient News: www.kidneypatientnews.org
- Renal Support Network: <http://www.RSNhope.org>
- American Association of Kidney Patients: www.aakp.org
- Fistula First Web Site: <http://www.fistulafirst.org>
- National Kidney and Urologic Diseases Information Clearinghouse: <http://www.kidney.niddk.nih.gov/kudiseases/pubs/vascularaccess/>

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