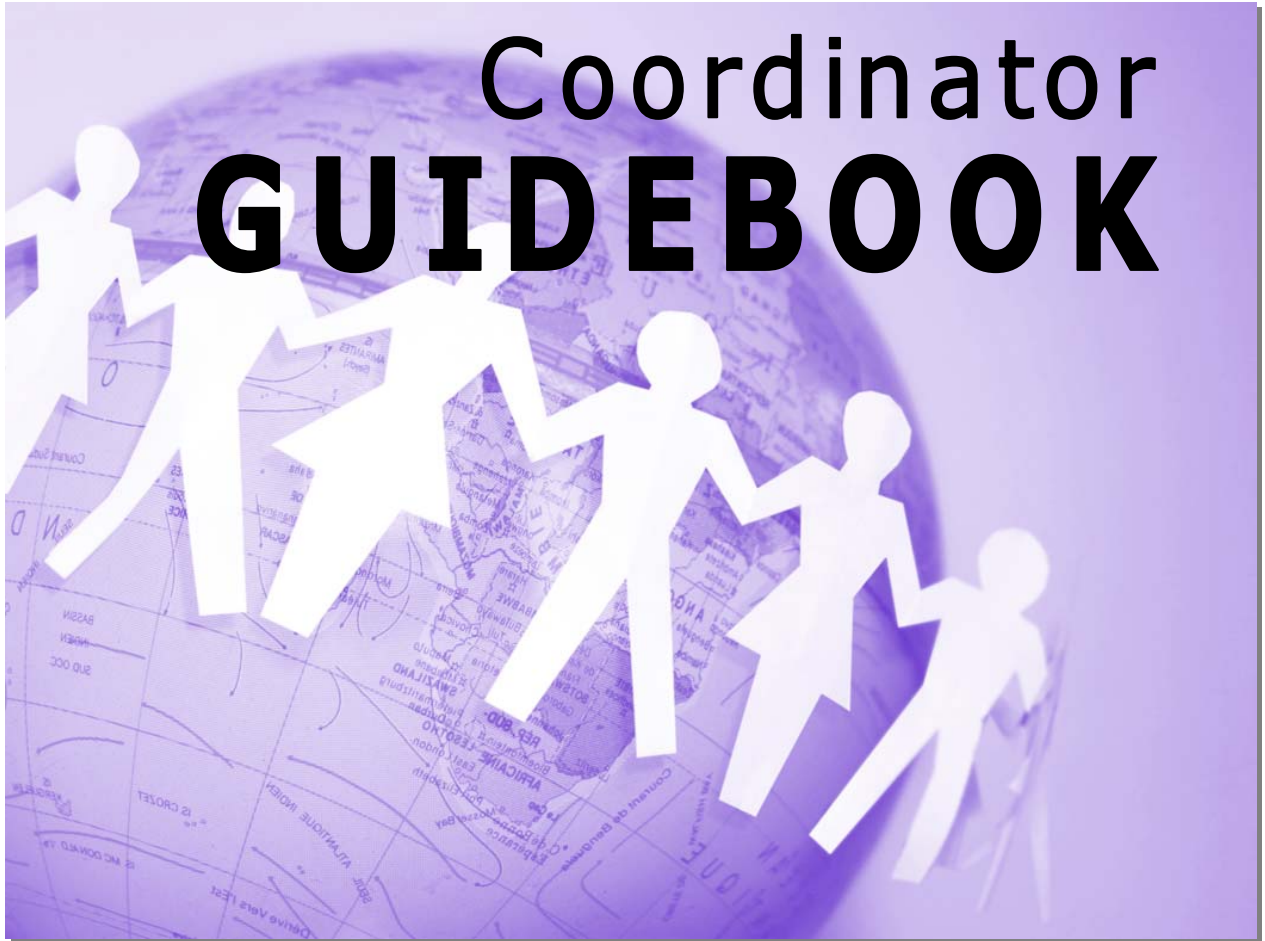




Coordinator **GUIDEBOOK**



**Fistula
Coaching
Program**

Preface

The Renal Network, Inc. wants to work with you to strengthen your patient fistula education program. The *Fistula Coaching Program* is a peer-to-peer coaching program that involves patients helping patients through positive communication, support in the planning and decision-making process. The Network Patient Leadership Committee was instrumental in its development.

We invite you to read both the *Fistula Coaching Program Coordinator Guidebook* and the *Patient Coach Handbook* and then to choose and train qualified patients to provide peer support and education to other patients who are hesitant about fistula placement. We encourage you to use the tools and materials selected for this program.

The Network Patient Services Department staff can help you in the development of your program if you need assistance. We encourage you to provide feedback on how you make use of the program and assist us by identifying its benefits as well as its weaknesses. Thank you in advance for your support of this program and for your feedback. We welcome the opportunity to work together in any aspect of the *Fistula Coaching Program*.

INTRODUCTION

The Fistula Coaching Program is designed to promote patient selection of the best vascular access choice through peer-to-peer education.

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

This facility-based program calls for the selection and training of patient volunteers to be active Fistula Patient Coaches. The role of the patient coach is to be available to patients who want to know more about having a fistula from someone who has been through the decision making process and has a healthy, mature and functional AV fistula. The patient coach can be trained to provide educational resources and support to the interested or hesitant patient contemplating an AV fistula.

To facilitate the implementation of the program two booklets were created:

- The Fistula Coaching Program *Coordinator Guidebook*, which outlines points for the facility to consider when it develops its training program.
- The Fistula Coaching Program *Patient Coach Handbook*, which provides tips and resources for the patient volunteer and can act as a workbook for the Coordinator to use in the training program.

The Fistula Coaching Program, developed by The Renal Network and its Patient Leadership Committee, is one resource to assist facilities with promoting fistula placement and overcoming barriers to AV fistula placement.

Feel free to reproduce the *Patient Coach Handbook* or any of the Network resources provided to use as part of your facility Fistula Coaching Program. The complete program is available on a CD-ROM or online at <http://www.therenalnetwork.org/services/FFcoach.php>. To obtain additional printed copies or to order a CD-ROM, please use the order form available in Appendix D.

This program is modeled on the Network Patient-to-Patient Program and supports the value of peer support and patients helping each other.

FISTULA COACHING PROGRAM

The Fistula Coaching Program requires that a facility staff member, 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 the patient coaches are following the policies and procedures of the facility. The *Patient Coach Handbook* may assist you in developing your facility Fistula Coaching Program. It provides information about what the coach does and does not do, provides suggestions on ways to approach patients who are in various stages of being interested in a fistula, provides communication and problem-solving tips, and discusses confidentiality.

COORDINATOR RESPONSIBILITIES

Determine Selection Criteria for the Patient Coach

When starting a new Fistula Coaching Program, it is important to have a well-defined idea of the right person for the job. Consider the following characteristics as you establish your selection criteria:

A. Hemodialysis status

- Copes well with kidney failure
- Has a working fistula
- Is fairly compliant
- Understands how to care for a fistula

B. Helping skills

- Wants to share this experience and knowledge to help fellow patients improve their quality of life
- Enjoys talking to others
- Accepts other points of view
- Respects others
- Knows and accepts that every situation will be different with each patient
- Has good listening and communication skills

Determine the Responsibilities of the Fistula Patient Coach

You may know in general what role you want the patient coach to fill and what you want them to do. Often the little details and the actual tasks required of the role may be difficult to come up with at first. This is an area, however, where it is better to be comprehensive as a way of maintaining good boundaries. The following are some suggested “do’s” and “don’ts”:

A. What the patient coach does:

- Visit the patient
- Listen attentively
- 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

B. What the patient coach does not do:

- Offer personal opinions
- Provide medical advice
- Compare his/her medical history to that of the patient
- Gossip about the unit staff, another patient, or patient family member
- Tell the patient what to do or not to do
- Pressure the patient in any way
- Get angry if the person decides not to get a fistula
- Make the patient feel bad or guilty if he/she decides against a fistula

Facilitate the Patient Coach Recruitment

Once the responsibilities of the patient coach have been established, shape your recruitment strategies to attract the best candidates. The following are some approaches to consider.

- Identify patients who are good role models; observe interactions with patients and staff members. Extend personal invitations to potential candidates.
- Promote the positive aspects of being a Fistula Patient Coach, such as mentoring and service.

- Involve former and current patient volunteers in the identification and recruitment process.
- To promote self-selection, consider posting recruitment information for patient coach volunteer positions.

Organize the Patient Coach Training Program

- Arrange training in small groups or one-on-one.
- Use the *Patient Coach Handbook* as your training tool. (Appendix E)
- Provide resources for the patient coach to share with patients. (Appendix A)
- Include facility guidelines on issues such as confidentiality and harassment.
- Provide a volunteer agreement form which includes reasons for release from program.
- Create a model for your peer-to-peer education program using one or more components, such as, one-to-one, special presentations or events, and regularly scheduled pre- or post-dialysis waiting room Q&A sessions.
- Provide overview of program supervision:
 - Assign coaching responsibilities.
 - Assign one-on-one coaching responsibilities from among patients requesting assistance from coaching program and granting permission for peer-to-peer coaching. You may use the *Vascular Access – Making Your Lifeline Choice* as a tool to match patients with a coach. (Appendix B)
 - Review areas/topics that the coach is free to address and discuss with the individual patient assigned.
 - Schedule meetings with the patient coach on a regular basis.
- Recognize the patient coach's efforts periodically through luncheons, bulletin boards, or small gifts.
- Evaluate and determine if the program seems to be beneficial to patients in your unit. Use the form provided in Appendix C for program feedback.

*If you have questions or need assistance in developing your training program, the Network staff is available to support you. Contact the Patient Services Department at (317)257-8265 or send an email to info@nw10.esrd.net using the subject heading: *Fistula Patient Coach Program*.*

Appendix A

Patient Coach Resources

Access Care: Your Lifeline - Provides information about vascular access. Included are tips on how to care for the access, problems that can develop and how to prevent them, and treatment options if a problem persists. (Revised edition)

Arterial Venous Fistula (AVF) - Provides general information gathered through a collaborative effort of Patient Services Coordinators from the 18 ESRD Networks across the nation.

Choosing Your Vascular Access - Provides information on the risks of catheters and the benefits of fistulas.

Ease the Ouch: Taking the fear out of AV Fistula Placement - This brochure is a discussion guide for patients, family members and healthcare staff to use when learning/informing people about fistula placement and managing fear.

Fistula First Patient Resources – A list of available resources compiled by FistulaFirst.org.

Renal Outreach – Reprints of articles featured in the Network patient newsletter:

- Frequently Asked Questions - AVF
- How Do I Look
- Naked Arm
- One-site-It is

Vascular Access – A collection of video shorts created by members of the Patient Leadership Committee available on DVD which outlines the benefits of AVF through the personal experiences of both patients and staff members.

Appendix B

Vascular Access – Making Your Lifeline Choice

A kidney patient’s choice of vascular access is one of the most important choices he or she will make while on dialysis. More evidence has emerged concluding that the AV fistula is the most effective and complication free access choice.

Has your nephrologist/staff talked to you about having an AV fistula placement?
(Please circle your answer.) Yes No

Have you ever refused AV fistula placement?
(Please circle your answer.) Yes No

If you have refused AV fistula placement, what factors affected your decision to refuse an AV fistula placement? (Please check all that apply.)

- | | |
|---|--|
| <input type="checkbox"/> Afraid of the big needles | <input type="checkbox"/> Don’t know enough about AV fistula to make a decision |
| <input type="checkbox"/> I’m too old | <input type="checkbox"/> Don’t want a scar |
| <input type="checkbox"/> Potential fistula problems – like excessive bleeding after treatment | <input type="checkbox"/> Don’t want to be stuck |
| <input type="checkbox"/> Don’t trust staff to stick me | <input type="checkbox"/> Generally afraid of having any surgery |
| <input type="checkbox"/> Don’t want another surgery | <input type="checkbox"/> Know patients with AV fistulas that have problems |
| <input type="checkbox"/> Don’t have time to stay and hold site after treatment | <input type="checkbox"/> Not experiencing a problem with my (please specify) _____ |
| <input type="checkbox"/> Can get on/off treatment easily with catheter | <input type="checkbox"/> PD is my treatment choice |
| <input type="checkbox"/> Doctor told me I can’t have one because (please specify) _____ | <input type="checkbox"/> Tried AV fistula but it didn’t work |
| <input type="checkbox"/> My access is my choice | <input type="checkbox"/> Want to wait until it is necessary |
| <input type="checkbox"/> Scared of pain | <input type="checkbox"/> On the transplant list – dialysis is temporary |
| <input type="checkbox"/> Patients with fistula don’t recommend it | <input type="checkbox"/> Afraid of blood, bleeding |
| <input type="checkbox"/> Won’t make a big difference in my outcomes, numbers | <input type="checkbox"/> Don’t like the way fistula looks |
| <input type="checkbox"/> Staff hasn’t encouraged it | <input type="checkbox"/> Other (please explain) |
| <input type="checkbox"/> Catheter is less noticeable | _____ |
| <input type="checkbox"/> AV fistula takes too much care | _____ |
| <input type="checkbox"/> Catheter is easier to maintain | _____ |

Appendix D

Fistula Coaching Program Materials Order Form

Please complete and return order form to Patient Services Department, The Renal Network, Inc.,
911 E. 86th Street, Suite 202, Indianapolis, Indiana 46240 or FAX to 317.257.8291.

CD-ROM

The CD includes all Fistula Coaching Program manuals and resources except the DVD which must be ordered separately.

of copies _____

PRINTED COPIES

Order all or selected program manuals and resources. Limit 10 copies per order.

- The Fistula Coaching Program *Coordinator Guidebook* # of copies _____
- The Fistula Coaching Program *Patient Coach Handbook* # of copies _____
- *Access Care: Your Lifeline* # of copies _____
- *Arterial Venous Fistula (AVF)* # of copies _____
- *Choosing Your Vascular Access* # of copies _____
- *Ease the Ouch: Taking the fear out of AV Fistula Placement* # of copies _____
- *Fistula First Patient Resources* # of copies _____
- *Renal Outreach*
 - Frequently Asked Questions – AVF # of copies _____
 - How Do I Look # of copies _____
 - Naked Arm # of copies _____
 - One-site-It is # of copies _____

Vascular Access DVD

of copies _____

NAME:			
TITLE:			
FACILITY:			
ADDRESS:			
CITY:		STATE:	ZIP:
EMAIL:			

Appendix E

Patient Coach Handbook

Provides tips and resources for the patient volunteer and can act as a workbook for the Coordinator to use in the training program.



The Renal Network, Inc.

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Email at: info@nw10.esrd.net
Web sites:
www.therenalnetwork.org
www.kidneypatientnews.org

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