Patients Helping Patients Learn About Kidney Care Choices

MODULE 3B REFERENCE GUIDE



End Stage Renal Disease National Coordinating Center 2015 Edition



Helping Peers Plan for a Vascular Access

Introduction

Welcome to Module 3B, "Helping Peers Plan for a Vascular Access." This module has four parts:

- Part 1: The Basics of Vascular Access
- Part 2: Introduction to the Vascular Access Resource Toolkit
- Part 3: Using the Toolkit
- Part 4: Tips to Remember

This module is designed to help you continue your training to become a peer mentor at your dialysis center, focusing on kidney transplant as an option.

Think back to when you were first told about your diagnosis that your kidneys were failing. Were you overwhelmed? Did you feel alone with this problem? Was it hard to remember and understand what you were being told? Maybe you felt like you received too much information in too short a time.



Looking back, do you feel that important information was not provided to you?



Newly diagnosed kidney patients must make decisions regarding many important questions, including:

- How should I receive treatment?
- What type of vascular access should I have?
- What can I do to prevent infections?
- Is transplant an option for me?

The decisions that newly diagnosed kidney patients make can affect their quality of life and experience of care.

In your role as a mentor, you can help a new kidney patient by sharing your personal experiences and offering educational resources and tools that will be provided as part of this program. You can encourage your peer to become engaged and active in care decisions. You can also help your peer connect with a member of his or her dialysis care team or someone at the ESRD Network for additional support and resources.

When you finish this module, you will be prepared to talk with your peers about vascular access.



...Let's get started!





Part 1: The Basics of Vascular Access

Why Do You Need a Vascular Access?

Healthy kidneys remove excess fluid and waste from your blood. When your kidneys lose their filtering ability, fluid and waste accumulate in your body — a condition known as kidney failure or end-stage kidney disease. When this happens, treatment by either dialysis or a kidney transplant is necessary.

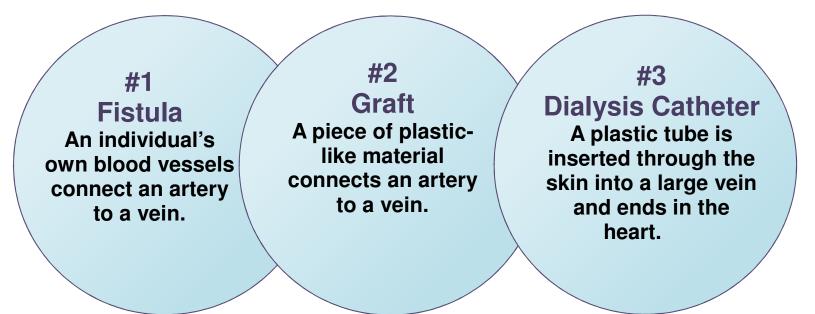
If hemodialysis is a person's treatment choice, a vascular access must be created or placed to provide special access for the treatment. Hemodialysis is a process that requires moving the blood in and out of the body to a filter that removes waste products and extra fluids from the body. A vascular access is created for that purpose.





Types of Vascular Access

There are three types of vascular accesses:



A fistula or graft is considered a permanent access. Once one is surgically implanted it can last a long time and be used repeatedly for dialysis treatment. A catheter has a higher risk of causing problems. It does not last as long as a fistula or a graft, and in most cases it is only a temporary access. A catheter should not be referred to as a "permcath."

A fistula is often considered the preferred type of access, since it has fewer complications and can last the longest of the three options. Patients should be educated about all three options so they can participate in decisions about vascular access with their healthcare team. As a mentor you'll be able to help your peers get information about vascular access and the different access types.



Vascular Access Planning for a Lifeline for a Lifetime

If hemodialysis is your peer's treatment choice, his or her vascular access will be a lifeline. A person's vascular access will be used more than 150 times each year! A vascular access plan will help ensure that the access is healthy and working correctly. An individual on hemodialysis may need more than one access is his or her lifetime.

A vascular access plan not only helps an individual get the best vascular access possible, but also helps him or her maintain an access, monitor it, and keep it healthy.

The plan will identify areas for future access, in case a replacement is needed down the road.





Importance of Mentoring to Support Access Planning

According to the United States Renal Data System (USRDS) 2014 report, 80% of those who start dialysis begin with a dialysis catheter. People who start dialysis with a catheter have a much greater risk of life threatening complications in their first year on hemodialysis.

Getting the vascular access that is right for an individual takes time and planning. There are steps to go through, and a permanent access has to mature or heal, depending on the type of access. A vascular access plan is more than just deciding on a vascular access; it also involves planning for how to maintain and monitor the access. When your peer starts a vascular access plan with the dialysis care team, he or she is moving in the right direction: toward a permanent access and better outcomes.





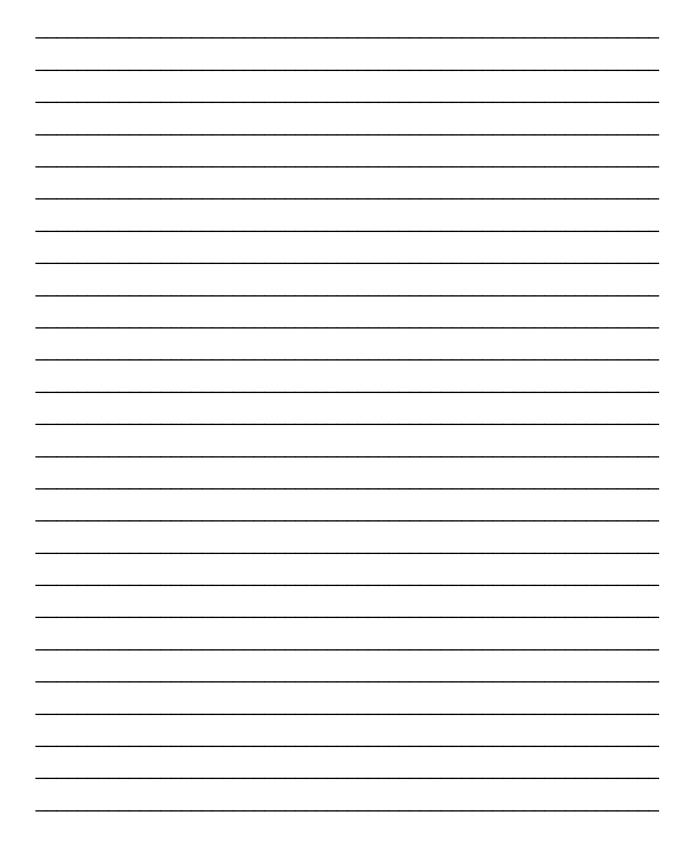
Your role as a peer mentor is to help support others in making these important decisions which affect their quality of life and experience of care. The earlier a peer starts the planning process, the better. Many dialysis patients will need a permanent vascular access at some point in their lives. Some people may need more than one.

Many people feel a sense of loss of control when they start dialysis. You may remember those feelings when you were new to dialysis. Perhaps you started with a catheter, and you now have a fistula or a graft as your permanent access. By mentoring and coaching your peer on developing a vascular access plan, you are helping him or her be involved and maintain a sense of control.





Notes





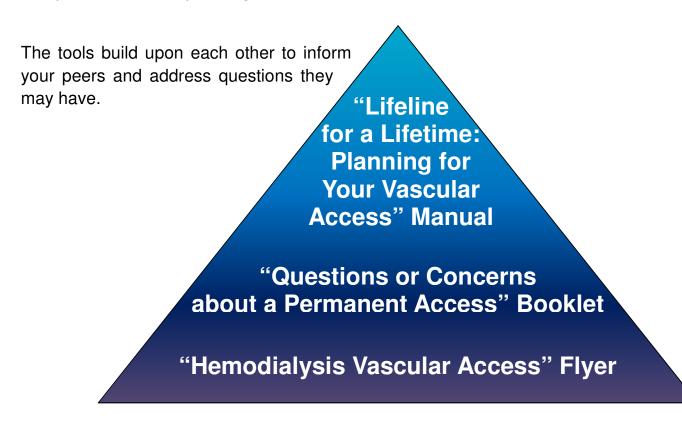
Part 2: Introduction to the Vascular Access Resource Toolkit

The materials in your Vascular Access Resource Toolkit will help you mentor peers about this kidney care choice. The toolkit includes three educational resources:

The first resource is the "**Hemodialysis Vascular Access**" Flyer, which covers basic information about the types of access for hemodialysis, how they are created, and facts to consider about each one.

The second tool is the "Questions or Concerns about a Permanent Access? Let's Talk!" Booklet, which reviews questions and concerns that your peers may have about getting a permanent access. It also suggests strategies to help them have some control in this process.

The third tool is the "**Planning for Your Vascular Access**" **Manual**, which is a comprehensive guide covering all the steps in getting a permanent access and achieving catheter freedom. It is the final tool in the toolkit, for peers who may be ready to start access planning.





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Part 3: Using the Resource Toolkit

Starting the Conversation about a Permanent Access

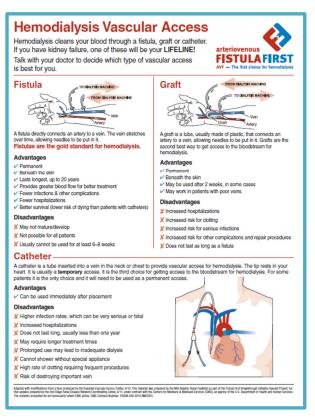
As you prepare to begin mentoring, remember that your peers may have different reasons for starting dialysis without a permanent access. Some of them may have had to start treatment on an emergency basis and didn't have time to plan for an access.

Others may have a health condition that prevented access surgery. Some may have been overwhelmed by all the information they had to process and the decisions they had to make when they were first diagnosed with kidney failure.

No matter what the reason may have been, it is important to begin sharing information that will help him or her make a decision about a permanent access.

Tool #1: "Hemodialysis Vascular Access" Flyer

This flyer gives basic facts about the three types of vascular access for hemodialysis, and the advantages and disadvantages of each. It's a helpful review for someone just starting to learn about a permanent access.





Fistula

This section of the flyer provides a brief description of what a fistula is and how it is built. A fistula directly connects an artery to a vein. The vein stretches over time, allowing needles to be put in for hemodialysis. A fistula is the gold standard for dialysis.

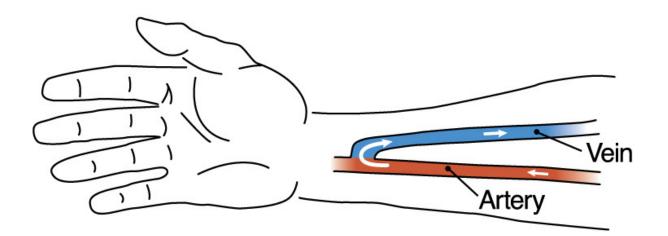
A fistula has several advantages over other types of access:

- It is permanent.
- It lasts the longest.
- People with fistulas have fewer infections, hospitalizations and other complications.

It also has some disadvantages:

- The fistula may not mature or develop enough for use.
- Some patients are not able to have a fistula.
- A fistula takes six to eight weeks to mature and grow.

A fistula is preferred when it is possible for the patient to have one because it is the access choice that lasts longest and has fewer complications in the long run.





Graft

Next, the flyer describes a graft and how it is made. A graft is a tube, usually made of plastic, which connects an artery to a vein, allowing needles to be put in it for hemodialysis. A graft is the second best choice for vascular access. Research shows it is a better choice than a catheter.

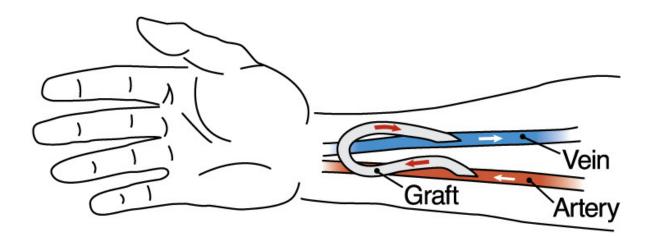
Advantages of a graft are:

- It is permanent.
- It normally may be used after three to four weeks.
- It may be effective for patients who cannot have a fistula.

Disadvantages of a graft include increased risk of:

- Hospitalizations.
- Clotting.
- Serious infections.
- Complications and repair procedures.

Most of the complications associated with a graft are related to having a piece of plastic inside your body, which is medically acceptable but not as good as your own blood vessels.



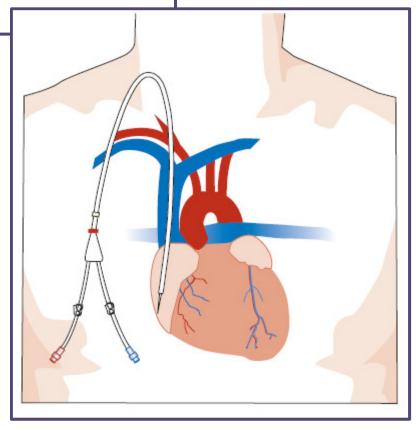


Dialysis Catheters

The flyer also provides information about hemodialysis catheters and the risks of using a catheter for dialysis.

Advantages Can be used immediately after placement Disadvantages Higher infection rates, which can be very serious or fatal Increased hospitalizations Does not last long, usually less than one year May require longer treatment times Prolonged use may lead to inadequate dialysis Cannot shower without special appliance

- X High rate of clotting requiring frequent procedures
- X Risk of destroying important vein





Using the "Hemodialysis Vascular Access" Flyer

If your peer doesn't have enough information or can't remember information he or she was given, share and review the "Hemodialysis Vascular Access Flyer." You may use this tool to open up discussion, find out what your peer already knows about vascular access, and learn if your peer needs more information at this point.

Always start with finding out your peer's understanding of the topic. The best way to do that is to ask your peer open-ended questions:

- What do you know about planning for a vascular access?
- How much were you told about the different access types?
- What type of information did you receive?
- What other information do you need?

These are questions that will help you start a conversation that will meet your peer's needs. If he or she is asking for more clinical information, connect your peer to the dialysis care team. What if your peer says he or she needs more time to think it over? Provide the flyer and let him or her know you will check in at another time.



If your peer wants to move toward an access plan, talk to your peer about his or her interest and share the Access Planning Guide. That is the third tool in the toolkit, which we will discuss below.

Remember, your approach depends on knowing where your peer is in the decision making process and meeting them there.

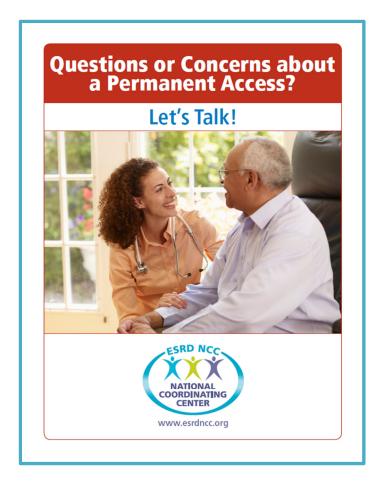


Tool #2: "Questions or Concerns about a Permanent Access? Let's Talk!" Booklet

Your peer may know basic information about vascular access but may have concerns about a permanent access. The second tool, "Questions or Concerns about a Permanent Access," is the right tool to share in this situation.

Many patients have concerns related to vascular access. Some common ones include:

- Being unsure about having surgery for the access, and worried about what that will entail in their current state of health.
- Worry or fear about use of needles during treatment.
- Concern about how a vascular access will look.
- Feeling nervous about possible complications.





Each of these areas is covered in the "Questions or Concerns about a **Permanent Access?**" booklet. This tool provides a guide to help your peer identify and work through concerns about permanent access placement, and discuss his or her worries and concerns with the healthcare team.

Does your peer have concerns about having the surgery for a permanent access? Share the tool and talk about the different concerns other patients have expressed. By reviewing the topics in this resource, you can help your peer identify and express his or her concerns.

What questions can your peer ask the healthcare team that will help him or her get information to overcome concerns? Use the tool and your experience to help your peer talk through these concerns.



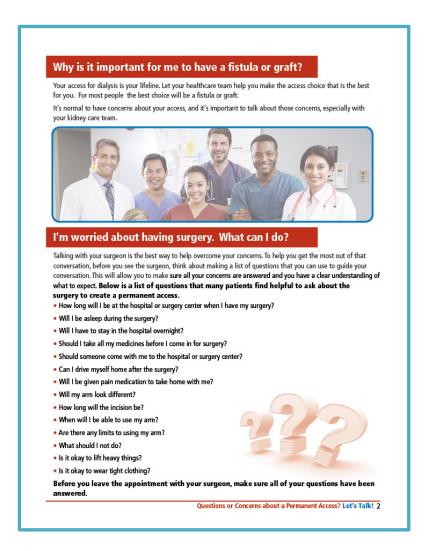


Using the "Questions or Concerns about a Permanent Access? Let's Talk" Booklet

Here are some examples of how this tool can be used to help your peer address concerns.

If your peer is concerned about access surgery, help create questions that he or she can ask the surgeon. The booklet contains a list of questions, which include:

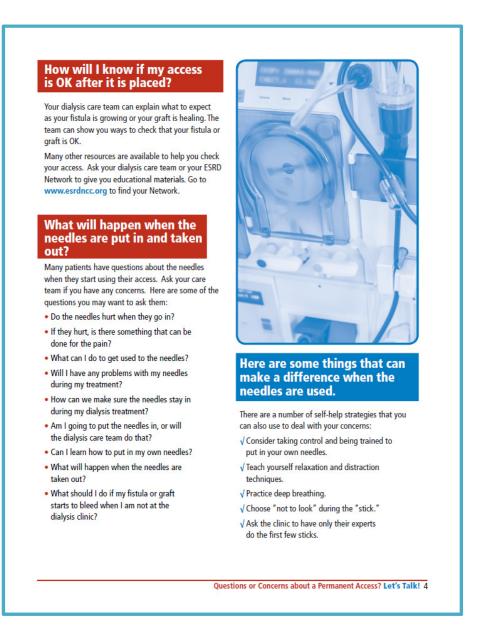
- Will I get pain medication?
- Will my access make my arm or leg look different?
- Will I be able to use my arm or leg?





If he or she is worried about needles, you can suggest strategies to manage this concern. The "Questions or Concerns about a Permanent Access" booklet offers a number of ideas, including:

- Talk to the healthcare team about medications or creams to numb the skin.
- Ask about self-cannulation (learning to put in the needles).
- Learn techniques to relax and distract from the needles.
- Review how you, as a peer, cope with needles.



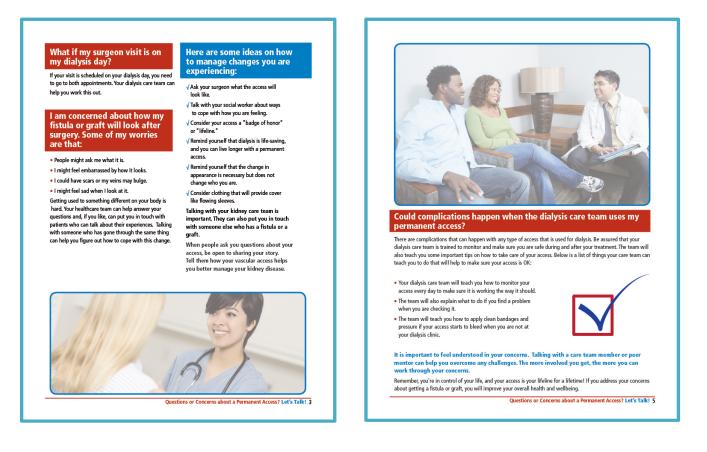


You should refer the peer to his or her healthcare team if concerns are related to complications that occur as a result of a permanent access. The healthcare team has been trained to manage complications and make sure treatment is safe. You can help your peer develop questions to ask the healthcare team about this concern. Questions could involve:

- What to do if the access is injured.
- What happens when the needles are taken out?
- What if the access starts bleeding when he or she is at home?

The appearance of the access is a worry to many people. You can review the section on how to accept changes in appearance with your peer. The booklet contains several suggestions for coping, including:

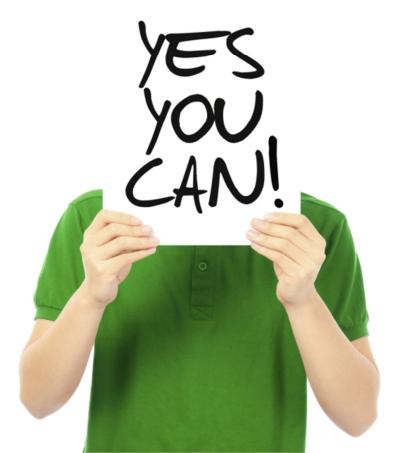
- Consider the access a "badge of honor" or "lifeline."
- Cover the access with loose wraps or flowing sleeves.





As a peer mentor, it's important for you to assess your peer's needs so you can decide the best way to help him or her. If your peer has concerns about getting a permanent access, you can share the tool and talk about the different concerns other patients have expressed. You can help your peer identify and talk about what is worrying him or her. Use the booklet and your experience to help your peer talk through any concerns, and direct him or her to the dialysis care for any medical questions.

Overcoming concerns is hard. You are helping your peer consider permanent access for dialysis, which is an important goal for living the best life on dialysis. Remember, your peer may not be able to overcome the concerns. He or she may not be willing or able to consider a permanent access. If that happens, it's okay. Remain supportive. Allowing your peer to talk about his or her concerns is a step in the right direction toward overcoming them.



You have succeeded as a mentor by sharing information and being there for your peer!



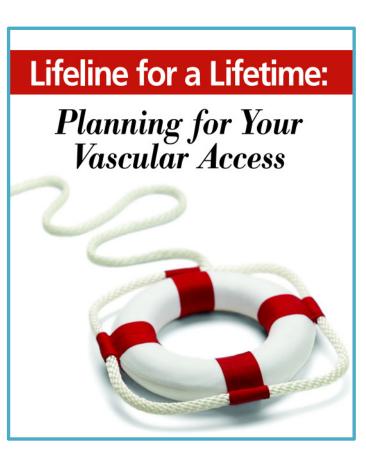
Tool #3: "Planning for Your Vascular Access" Manual

When your peer is ready to move on to planning for a vascular access, your next step is to review the "Planning for Your Vascular Access" manual.

This is a detailed guide that covers each step of the process in getting a vascular access. The manual starts with a description of treatment choices.

Then it explains the eight steps necessary to get a permanent access, which are:

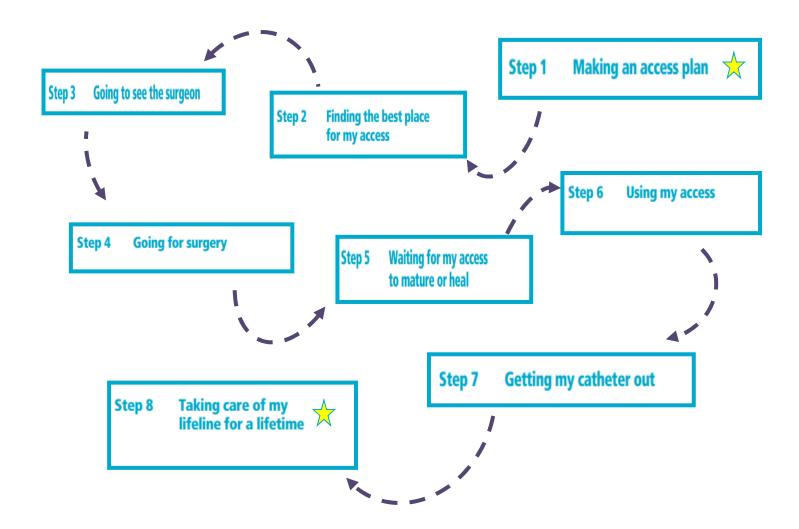
- Making an access plan.
- Finding the best place for the access.
- Going to see the surgeon.
- Going for surgery.
- Waiting for the access to mature or heal.
- Using the fistula or graft.
- Getting the catheter taken out.
- Taking care of the lifeline for a lifetime.





As always, assess your peer's needs before you share this manual. Your peer may know what a permanent access is, but may not have a plan or know what it entails. Ask open-ended questions. Does your peer have an access plan? Where is he or she in the process? Does your peer have questions about the steps in the plan? How can you help your peer learn about and move through the steps?

Supporting your peer may be complicated. Finding where your peer is in the process and helping him or her move through the steps is an important part of your role and can help your peer succeed. As your peer moves through the planning process, you can help him or her write down a schedule for each step.





Using the "Planning for Your Vascular Access" Manual

Step 1: Making an Access Plan

This resource outlines the process that needs to be followed in order to achieve catheter freedom. Often people don't start with a plan. They may know they need a permanent access and set out to get one without knowing what is involved.

Developing a plan with the dialysis care team will help your peer understand what to expect with each step in the process. Your peer will be able to track each of the steps as he or she works through the plan made especially for him or her.

Page 25 of 46

Take time and be patient through the process.

If things slow down or don't go as planned, your peer can work with the dialysis care team to find solutions.

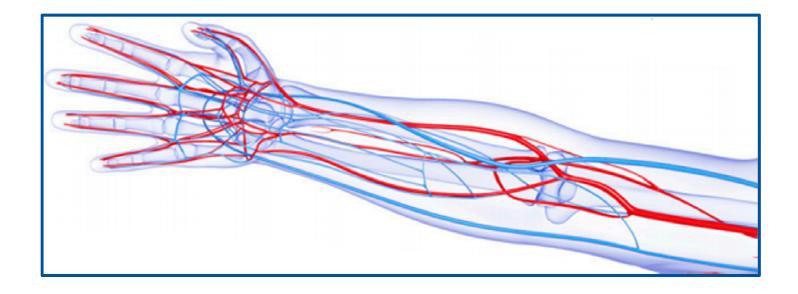


Step 2: Finding the Best Place for the Access

This step describes a procedure called vessel mapping, which creates a picture of the blood vessels.

This is done to help the surgeon find the best place to put the access, where the blood vessels are big enough for a fistula or graft. Sometimes vessel mapping is done in the surgeon's office.

In other cases your peer will go to a different office to get the procedure done.





Step 3: Going to See the Surgeon

The first appointment with the surgeon is very important. Always help your peer prepare for the appointment and understand what will happen. The first appointment helps the surgeon to decide where the fistula or graft should go. The surgery will not be performed during the first appointment.

If the surgeon's office can only make an appointment during a time when your peer has dialysis treatment scheduled, help your peer work with the dialysis care team to reschedule dialysis treatment. Both appointments need to take place, and both need to happen at the right time.

Going to see the surgeon can be very stressful. Many people are nervous about this visit. Being prepared is a great way to work through the stress. You can help your peer prepare for the surgeon visit by reviewing the list of questions in the manual, so he or she can select ones to ask that are important to him or her.



Your peer may have other questions as well. Your peer may have to wait to be scheduled for surgery.

Talk about tips to stay healthy while going through this process, and help your peer work out scheduling questions.



Step 4: Going for Surgery

This step is perhaps the most stressful step in the whole access placement process. There is always a lot of information that the surgeon's office must have before the surgery, and your peer will need to make arrangements for the surgery.

How can you help your peer get ready?

- Review the list of information your peer may need to provide to the surgery team.
- Ensure that your peer has made transportation arrangements to and from the surgery facility and has directions to get there. Does your peer have "going home" instructions and information on what happens while waiting for the access to heal? If not, he or she should ask for these. Is there a care partner or someone else who can help him or her with this part of the process?
- Direct your peer to the healthcare team if he or she has medical questions or concerns about the schedule.

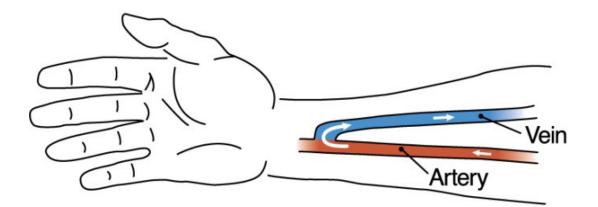




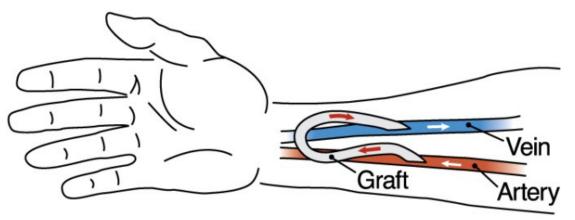
Step 5: Waiting for the Access to Mature or Heal

The waiting time to use a new access depends on whether the access is a fistula or a graft.

Fistulas require a few weeks to grow big enough to use, which is called maturing. The surgeon will tell your peer how long the process is likely to take.



Grafts have to heal, but they don't grow over time. Grafts are usually ready for use a little sooner than a fistula, in about three or four weeks. Again, the surgeon should tell your peer how long he or she thinks it will be before the graft can be used.





In either case, if the information hasn't been provided, encourage your peer to ask the surgeon. Sometimes the access may not mature or heal as expected, or there may be a complication.

The sooner your peer reacts to a problem, the better the chances for a solution. There is advice in the access planning guide on how to handle these problems. Your peer should know that a problem does not necessarily mean that his or her surgeon has done a bad job.

Sometimes these things just happen when surgery is done. The best action your peer can take is to watch the new access and tell the dialysis care team if it looks or feels like something is wrong. The best action you can take is to support your peer through this process.





Step 6: Using the Access

When the dialysis care team starts to use the access your peer may feel nervous or concerned. You can help your peer get ready for using the access:

- Review the daily access check, "Look," "Listen," and "Feel."
- If your peer is concerned about needles, review the list of questions in the planning guide appendix to help work through those concerns.
- If your peer doesn't know the plan for using the access, connect him or her to the healthcare team. The healthcare team will communicate with the surgeon and monitor the access as it is maturing or healing. The team will have information about when the access is ready to use.

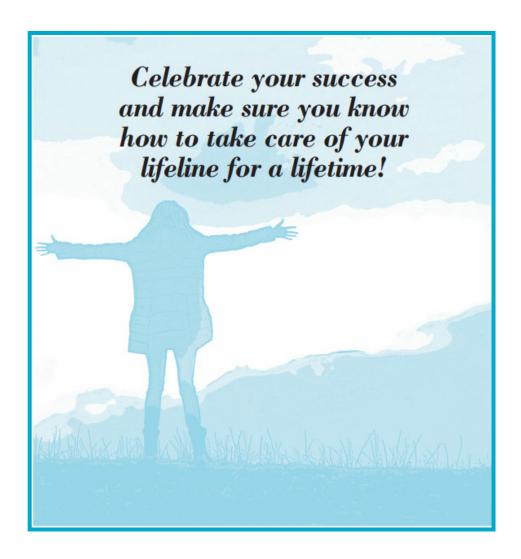




Step 7: Getting the Catheter Out

Before the catheter is taken out, most dialysis care teams will want to use the access with two needles for several treatments. If they feel the process is going well and they are getting the blood supply they need for treatment, the team will schedule your peer for an appointment to have the catheter removed.

This is a huge success! Your peer should celebrate catheter freedom. He or she has taken a big step by creating a lifeline for a lifetime.





Step 8: Taking Care of the Lifeline for a Lifetime

Emphasize to your peer that checking the access every day is an important step in taking care of a fistula or graft. Doing this daily check helps ensure the lifeline will last a lifetime. The one minute access check guides your peer on how to make sure the access is working.

The dialysis care team can help him or her learn to do the check. It's also important that your peer knows who to contact if a problem should arise with the access.





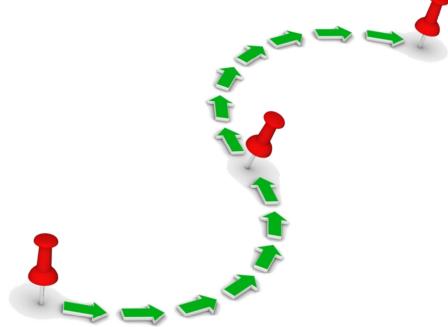
Part 4: Tips to Remember

Starting a Vascular Access Plan

As you take your peers through the toolkit and the access planning manual we just reviewed, remember that everyone won't start at the same step. For example:

- Those who have only a catheter start at Step 1, right at the beginning of the access plan.
- If your peer is still using a catheter but is waiting for a fistula or graft to mature or heal, they start at Step 1 and go to Step 5.
- Those who are using a fistula or graft without a catheter start at Step 1 and can go right to Step 8, the one minute access check.

When you coach your peer on access planning, remember that he or she can move to whatever step makes the most sense, based on where he or she is in the process.





Ideally, new patients should have an access plan created before they start dialysis. All new and established dialysis patients should have an access plan specific to their access status.

The access plan should be used in all sites of care including the:

- Dialysis clinic,
- Access center,
- Hospital,
- Outpatient facility,
- Or other offices or clinics.

If your peer requires care for another condition, it's important that he or she bring the access plan and inform that care team about his or her access. A vascular access is a lifeline for a lifetime and an important part of his or her medical



background.

There is a page in the "**Planning for Your Vascular Access**" manual for an individual to record his or her access plan. Encourage your peer to always take the plan when he or she speaks to other healthcare teams.



Tips for Supporting Your Peer

Once you have completed reviewing the Vascular Access Toolkit with your peer, it is up to your peer to take the necessary actions needed to begin a plan. Encourage your peer to talk to a member of his or her dialysis care team about starting a vascular access plan.

He or she should ask the dialysis care team to help develop and work through the steps of the access plan. *No patient can do this alone*. If your peer decides to talk to the dialysis care team about access planning, celebrate that choice and encourage him or her.





Your peer may not want to proceed at this point, and that is OK! You have succeeded in your role as a mentor by providing him or her with important information. Support and celebrate the decision your peer makes.

Check in with your peer often to:

- Help connect him or her with the dialysis care team.
- Provide encouragement if he or she runs into obstacles.
- Answer questions along the way.
- Reinforce using the toolkit for information.
- Offer support in dealing with issues.

The relationship does not stop when you finish sharing all of the information with your peer. If he or she runs into any problems, you can help connect your peer with someone on the dialysis care team to talk about them. If there are more questions along the way, you can help to reinforce the information in the toolkit.





There are other options for treatment that your peer can consider. Ultimately the best choice is the one that is right for him or her. Your role as a mentor is to give your peers the information that they need so they can be educated and informed.

They can then make choices based on their needs and will know when to talk to their care team.

Important Additional Resources

Your ESRD Network has several resources that can help you and your peers learn more about treatment choices. Several renal organizations also provide educational resources for kidney patients. Feel free to share this information with

your peers so they can do additional research on their own. You can also ask your point of contact at your center for additional resources and for any support you might need throughout the mentoring process.





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Next Steps

Congratulations! You have successfully completed Module 3B.

Please complete the Module 3B: Helping Peers Plan for a Vascular Access Review Quiz and provide your results to your facility point of contact.

Once you complete the Review Quiz, you will be a certified ESRD NCC Vascular Access Peer Mentor! Your point of contact will let you know what tools you need to review to support your mentorship program. You can review your plans with your facility point of contact, and get ready to begin mentoring peers.

Thank you for taking our training course! For additional information, contact us at <u>ncc@ncc.esrd.net</u>.





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Review Quiz Questions

Please answer the following questions to earn your Module 3B completion badge. You can review your quiz results with your facility point of contact for this peer mentoring program.

1. Fistulas or grafts are preferred over catheters.



False

- 2. Catheters are considered permanent vascular accesses?
 - True

False

3. Having a vascular access plan helps to promote:

Getting the best vascular access possible.

Proper maintenance and monitoring of the access.

Identification of future areas for an access.

Additional Maintenance of those areas for future use.

All of the above.

None of the above.

Continue to next page.



4. How many steps are there to creating a vascular access plan?

□1 □3

B

12

5. The peer should ask the dialysis care team to help develop and work through the steps of the access plan.

True

False



Review Quiz Answers

BOLD = CORRECT ANSWER

1. Fistulas or grafts are preferred over catheters.

⊡True

False

2. Catheters are considered permanent vascular accesses?

True

False

3. Having a plan helps to promote:

Getting the best vascular access possible.

Proper maintenance and monitoring of the access.

Identification of future areas for an access.

Maintenance of those areas for future use.

All of the above.

None of the above.

Continue to next page.



4. How many steps are there to creating a vascular access plan?

□1 □3

⊠8

12

5. The peer should ask the dialysis care team to help develop and work through the steps of the access plan.

⊘True

False





End Stage Renal Disease National Coordinating Center

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