

# WHAT'S YOUR PLAN?

This resource was created by patients for patients, with the goals of:

- Getting more patients engaged in their dialysis Plans of Care (POC).
- Encouraging dialysis facilities to hold POC meetings with patients.
- Inspiring patients to attend their POC meetings.



This [What's Your Plan?](#) brochure will help you:

- Communicate better with your dialysis healthcare team.
- Understand your dialysis POC.
- Know the benefits of understanding your plan.
- Get prepared for your dialysis POC meeting.

Ask your nurse or social worker today about your dialysis POC, and how to ensure you will be able to attend your POC meeting.

***YOU are the most important member of your dialysis healthcare team!***

# MY PLAN: How to Talk to Your Healthcare Team

## **WHO IS ON MY HEALTHCARE TEAM?**

Your healthcare team is you and the staff who cares for you. Your doctor is like the “head coach,” and your social worker, dietitian, nurses, and techs are part of the team. You may also have a family doctor and see other specialists. The most important member of your team is *you*.

## **WHY AM I THE MOST IMPORTANT TEAM MEMBER?**

Because it is *your* life and *your* treatment. Being an involved dialysis patient means you partner with other team members in all aspects of your treatment plan. It’s the best way to address any concerns or questions you may have, and it will help you learn about your dialysis care.

Your care team needs to know how you feel, both physically and emotionally. They want to know what concerns you have so they can help you follow your medication, treatment, and diet plans, as well as help you to set and reach realistic goals.



## **WHAT DOES MY TEAM DO FOR ME?**

- Your team’s goal is to keep you healthy.
- Your dialysis doctor prescribes medicines and follows your care.
- Nurses and technicians make sure you get safe, effective dialysis based on your doctor’s orders.
- Your dietitian teaches you to plan renal-smart meals.
- Your social worker can help you and your family cope with the challenges of dialysis and help you sign up for additional services for which you may be eligible.

## **HOW SHOULD I TALK TO MY HEALTHCARE TEAM?**

- Ask questions! Patients who study their options and help make decisions about their care are stronger members of their care teams.
- Write your questions down so you don’t forget them.
- Ask your most important question first.
- Repeat back the answers you hear and write them down.
- Don’t be afraid to ask if you don’t know the meaning of a medical term.
- Be as clear as you can when you have a problem.
- Enlist a caregiver or family member to help you communicate with your team.

## HOW CAN I MAKE SURE I GET WHAT I NEED FROM MY HEALTHCARE TEAM?

| Concern   | How can I prevent it?   | What should I ask?   |
|---|---|--|
| I always feel so rushed.  | <ul style="list-style-type: none"> <li>• Before an appointment, write down your questions.</li> <li>• Don't get sidetracked by small talk. Be pleasant but make sure you get meaningful answers to all of your questions.</li> <li>• If you run out of time, make another appointment.</li> </ul>   | <ul style="list-style-type: none"> <li>• I wrote down some questions. Can you please answer them for me before I leave?</li> </ul>   |
| After I've seen my doctor, I have a hard time telling my family what she/he said to me. | <ul style="list-style-type: none"> <li>• Repeat what the doctor said back to him/her to be sure you understand.</li> <li>• Write down what you heard.</li> <li>• Bring a family member to the appointment if you can.</li> <li>• Ask if there is written information you can take home to your family.</li> </ul>   | <ul style="list-style-type: none"> <li>• Can I tell you what I heard you say, so you can tell me if I heard it right?</li> <li>• Do you have a pamphlet on this problem that I could take home with me?</li> </ul> |
| There is so much about my kidney disease I don't understand.                            | <ul style="list-style-type: none"> <li>• List the things that confuse you.</li> <li>• Ask the social worker to help you find people to answer your questions.</li> <li>• Go to the library and do your own research.</li> <li>• Join an American Association Kidney Patients or National Kidney Foundation chapter (see below) to learn from other patients.</li> </ul> | <ul style="list-style-type: none"> <li>• Who is the best person on my team to ask about _____?</li> <li>• Do you have anything I could read about _____?</li> </ul>  |

Used with permission from Life Options Rehabilitation Program: [www.lifeoptions.org](http://www.lifeoptions.org)

## WHERE CAN I FIND OUT MORE ABOUT WORKING WITH MY HEALTHCARE TEAM?

- HSAG: ESRD Network 13: 800.472.8664/ <https://www.hsag.com/en/esrd-networks/esrd-network-13/>
- Life Options Rehabilitation Program: 800.468.7777/ [www.kidneyschool.org](http://www.kidneyschool.org).
- The American Association of Kidney Patients (AAKP): 800.749.AAKP/ [www.aakp.org](http://www.aakp.org).
- The National Kidney Foundation (NKF): 800.622.9010/[www.kidney.org](http://www.kidney.org).
- Renal Support Network: 866.903.1728/<http://www.rsnhope.org>.
- Dialysis Patient Citizens: 855.291.3725/<http://www.dialysispatients.org>.

## MY PLAN: *What You Need to Know About Your Plan*

The POC meeting is your opportunity to communicate directly with your healthcare team about decisions that affect your dialysis care and to get the maximum benefit from each treatment for your overall health and well-being. You will learn more about End Stage Renal Disease (ESRD) and how your choices affect various aspects of your treatment. During the POC meeting, your healthcare team will answer your questions and concerns regarding your care, so you can be an informed, engaged patient.



### **YOUR POC WILL ADDRESS:**

- The dose of your dialysis (such as the length of your treatment)
- Adequacy of treatment (how well dialysis is cleaning your blood)
- Nutritional status
- Mineral metabolism or bone health (phosphorus, calcium, PTH, etc.)
- Anemia (hemoglobin levels and Epogen use)
- Vascular access (fistula, graft, or catheter)
- Psychosocial status (your level of adjustment to dialysis, insurance coverage, etc.)
- Your treatment type and preferences (home hemodialysis, in-center hemodialysis, peritoneal dialysis)
- Transplant status and preferences
- Rehabilitation status (are you employed, retired, desiring to return to work)

### **HOW OFTEN IS MY POC COMPLETED?**

The POC is completed when you initially start dialysis, three months after starting dialysis, and yearly thereafter. A POC is also completed any time your health condition changes, for example, after several hospitalizations or if you have a significant change in your personal life (death of a loved one) or changes in mental health.

### **HOW DO I FIND OUT WHEN MY POC WILL BE REVIEWED?**

Ask your facility when and where your next POC meeting will be held.

### **WHAT IF I CANNOT ATTEND WHEN THE MEETING IS SCHEDULED?**

Talk with your facility about alternatives.

- Can the meeting be held at a different time or date?
- Can you participate by telephone?

Since you are the most important part of the care team, let your facility know that you want to participate and discuss options that will allow you to participate.

## **Patient Perspective**

We, as patients, should be aware that we are an integral part of the POC process. During this meeting, it is important to participate and provide information regarding our health/treatment, as well as, be informed by members of our team. Although, the POC is usually done chair side while we dialyze, we have the choice to meet with other members of the team in an office to ensure confidentiality. Being a part of the team enables us to have a voice and feel as though we are talked *to* and not talked *at*.

*Clois C., Baton Rouge, LA*

### **MY RIGHT TO TAKE PART IN MY CARE AND TREATMENT**

#### **I have the right to:**

- Be told about my rights and responsibilities
- Be treated with respect
- Privacy: My medical records can't be shared with anyone, unless I say so
- Dietitian and Social Work services
- Be told about my health in a way that I understand
- Be told about and choose my treatment options
- Be told about any tests ordered for me and their results
- Be told about the services offered at the center
- Be told about the process of dialysis and dialyzer re-use
- Be told about any expenses that I have to pay for if they are not covered by insurance or Medicare
- Be told about any financial help available to me
- Accept or refuse any treatment or medicine my doctor orders for me
- Be told about the rules at the treatment center (for example, rules for visitors, eating, and personal conduct)
- Choose if I want to be part of any research studies

#### **My job is to:**

- Tell my healthcare team if I don't understand my medical condition or treatment plan
- Treat other patients and staff as I would like to be treated, with respect
- Tell my healthcare team if I refuse any treatment or medicine that my doctor has ordered for me
- Tell my healthcare team if I have medical problems, am going to the dentist, am being treated by another doctor, or have recently been to the hospital
- Follow the rules of the dialysis center
- Get to and from the center for my treatments; I can talk with my social worker if I need help doing this
- To pay my bills on time; If this is hard for me, I can ask about a payment plan

Source: <http://medicare.gov/DialysisFacilityCompare/Resources/Patients-Rights.html>

# MY PLAN: Patient Plan of Care Meeting

Get ready for your POC meeting with this checklist created by patients, for patients.

## **BEFORE THE MEETING:**

- Ask your care team when your POC meeting will be scheduled.
- If you don't want to return to the facility for a meeting on your day off, ask for a date and time that works for your schedule, or ask about the possibility of a phone conference.
- Ask that the facility staff remind you of the meeting the day before.
- Ask for an interpreter, if needed.
- Ask for a copy of the POC that the other members of the team have completed prior to the meeting. It should include:
  - The dose of your dialysis (including the length of your treatment)
  - Adequacy of treatment (how well dialysis is cleaning your blood)
  - Your nutritional status
  - The status of your mineral metabolism and/or bone health (phosphorus, calcium, PTH, etc.)
  - Whether or not you have anemia (hemoglobin levels, IV Iron and Epogen administration)
  - Your vascular access type (fistula, graft, or catheter)
  - Your psychosocial status (your level of adjustment to dialysis, insurance coverage, etc.)
  - Your treatment type and preferences (home hemodialysis, in-center hemodialysis, peritoneal dialysis)
  - Your transplant status and preferences
  - Your rehabilitation status (employed, retired, desiring to return to work)
- If your lab results are not included on the POC, ask your healthcare team for the latest copy.
- Ask a family member or friend to attend the meeting with you. Your facility may have a patient advocate that could attend with you if you would prefer.
- Make a list of questions, concerns, and observations you may want to discuss. for example: sleeping problems, muscle cramping, feelings of sadness, issues with staff.
- Make a list of all the medications you are currently taking, including over-the-counter medications and vitamins or supplements, and bring it to the meeting.





**To file a grievance about the care you are receiving at your dialysis facility, contact Network 13 at 1.800.472.8664.**

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