# What's Your Plan?

HSAG HEALTH SERVICES ADVISORY GROUP

ESRD Networks 7, 13, 15, 17, 18

## 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?* booklet 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!**

# 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 technicians are part of the team. You also may have a primary care 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 health and your treatment. Being an involved dialysis patient means you partner with other team members in all aspects of your treatment plan. It is 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 set and reach your 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.
- Your dietitian teaches you to eat renal-smart meals.
- Your social worker can help you and your family cope with the challenges of dialysis and help you sign up for services to support you.

## 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 do not forget them.
- Ask your most important question first.
- Repeat the answers you hear back to your care team and write them down.
- Do not be afraid to ask the meaning of a medical term.
- Be as clear as you can when you have a problem.
- Involve a care partner, friend, 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 rushed during my medical appointments. | • Before an appointment, write down your questions.<br>• Do not get distracted by small talk. Be pleasant but make sure you get answers to all your questions.<br>• If you run out of time, make another appointment. | • I wrote down some questions. Can you please answer them for me before I leave? |
| After I have seen my doctor, I have a hard time telling my family what she/he said to me. | • Repeat what the doctor said back to her/him to be sure you understand.<br>• Write down what you heard.<br>• Try to bring a care partner, friend, or family member with you to the appointment.<br>• Ask if there is written information you can take home to your family. | • Can I tell you what I heard you say, so you can tell me if I heard it right?<br>• Do you have a pamphlet on this problem that I could take home with me? |
| There is so much about my kidney disease I do not understand. | • List the things that confuse you.<br>• Ask the social worker to help you find people to answer your questions.<br>• Go to the library and do your own research.<br>• Join an American Association of Kidney Patients or National Kidney Foundation chapter (see below) to learn from other patients. | • Who is the best person on my team to ask about ________________________ ?<br>• Do you have anything I could read about ________________________ ? |

Used with permission from Life Options Rehabilitation Program: www.lifeoptions.org

## Where can I find out more about working with my healthcare team?

- HSAG: End Stage Renal Disease (ESRD) Networks webpage: www.hsag.com/en/esrd-networks
- Life Options Rehabilitation Program: www.kidneyschool.org
- The American Association of Kidney Patients (AAKP): www.aakp.org
- The National Kidney Foundation (NKF): www.kidney.org
- Renal Support Network: www.rsnhope.org
- Dialysis Patient Citizens: www.dialysispatients.org

# What You Need to Know About Your Plan

The POC meeting is your opportunity to talk with your healthcare team about decisions that affect your dialysis care and to get the maximum benefit from each treatment for your overall health. You will learn more about 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.

## Your POC addresses:

- The dose of your dialysis (such as the length of your treatment)
- Adequacy of treatment (how well dialysis is cleaning your blood)
- Nutritional status (if you are eating the right amounts of different foods)
- Mineral metabolism or bone health (phosphorus, calcium, and parathyroid hormone [PTH] lab values)
- Anemia (hemoglobin levels and Epogen® and/or iron doses)
- 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, or peritoneal dialysis)
- Transplant status and preferences
- Rehabilitation status (are you employed, retired, want to return to work or school, or volunteer)

## How often is my POC?

The POC is completed within 30 days of starting dialysis, three months after starting dialysis, and yearly after that. A POC is also completed any time your health condition changes, for example, after a long hospitalization or a significant change in your personal life (loss of a job, 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 other meeting options.

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

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

## Patient perspective:

"I have been on hemodialysis for 35 years, and when people ask what's my secret? Here it is …

- Never miss or cut a treatment.
- Learn your diet and follow it.
- Always remember that the dialysis staff are there to help. They're part of your 'team.'
- Ask questions and be kind.
- Think of dialysis as your new job and make sure that you excel at it—your life depends on it!
- Step-up and take ownership of your health and healthcare.

You can not only survive, but you can thrive. It is all in your hands!"

*—Amy M., Network Patient Advisory Committee Member*

## My right to take part in my care and treatment:

### I have the right to:

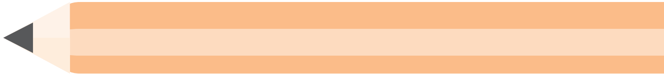
- Be told about my rights and responsibilities.
- Be treated with respect.
- Privacy. My medical records can't be shared with anyone, unless I say so.
- Meet with my whole healthcare team to plan my treatment.
- Dietitian and social work services.
- Be told about my health in a way that I understand.
- 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 expenses that I must pay if they are not covered by insurance or Medicare.
- Be told about 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:

- Treat other patients and staff as I would like to be treated, with respect.
- Pay my bills on time. If this is hard for me, I can ask about a payment plan.
- Tell my healthcare team if I refuse any treatment or medicine that my doctor has ordered for me.
- Tell my healthcare team if I don't understand my medical condition or treatment plan.
- Be on time for my treatments or when I see my doctor.
- Tell the staff at the center if I know that I'm going to be late or miss a treatment or visit with my doctor.
- 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 center.
- Get to and from the center for my treatments. I can talk with my social worker if I need help doing this. Medicare doesn't pay for transportation.

Source: Medcare.gov. Find & Compare Providers Near You. Available at [www.medicare.gov/care-compare/resources/resources-and-information](www.medicare.gov/care-compare/resources/resources-and-information). Accessed on March 31, 2025.

# Patient POC 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 do not want to return to the facility for a meeting on your day off, ask for a date and time that works for you, or ask about the possibility of a phone conference.**

☐ **Ask the facility staff to remind you of the meeting the day before.**

☐ **Ask for an interpreter, if needed.**

☐ **Ask for a copy of the POC that has been completed prior to the meeting. It should include:**

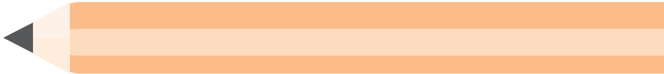
- The dose of your dialysis (including the length of your treatment)
- Adequacy of treatment (how well dialysis is cleaning your blood)
- Your nutritional status
- The status of your mineral metabolism or bone health (phosphorus, calcium, and PTH lab values)
- Whether or not you have anemia (hemoglobin levels, iron and Epogen® prescriptions)
- 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, wanting to return to work or school or volunteer)

☐ **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.**

☐ **Bring all current medications with you or a list of all current medications, including over-the-counter medications and vitamins or supplements, and bring it to the meeting.**



**During the meeting:**

- ☐ If not provided, request your own copy of the POC that has been completed.
- ☐ Check the medications listed on the POC to be sure they are correct.
- ☐ Review your dialysis treatment lab results (dialyzer clearance and time/volume [Kt/V], urea reduction ratio [URR]), to make sure you are receiving the right amount of treatment for *you*.
- ☐ Bring your list of questions and concerns. Ask your questions or talk about your concerns.
- ☐ Ask if other members of the team have concerns related to your POC.
- ☐ Write your comments on the POC document.
- ☐ Request that any changes in your POC during the meeting are included prior to you signing the POC document. Keep a signed copy for your records. You may want to compare this POC to your next version.

**Your questions or concerns:**

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## If you have questions or to file a grievance about the care you are receiving at your dialysis facility, contact your ESRD Network listed below:

**Network 7: Florida**

800.826.3773

**Network 13: Arkansas, Louisiana, Oklahoma**

800.472.8664

**Network 15: Arizona, Colorado, Nevada, New Mexico, Utah, Wyoming**

800.783.8818

**Network 17: American Samoa Guam, Hawaii, Northern California, Northern Mariana Islands**

800.232.3773

**Network 18: Southern California**

800.637.4767

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