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!
**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?

<table>
<thead>
<tr>
<th>Concern</th>
<th>How can I prevent it?</th>
<th>What should I ask?</th>
</tr>
</thead>
<tbody>
<tr>
<td>I always feel so rushed.</td>
<td>• Before an appointment, write down your questions.</td>
<td>• I wrote down some questions. Can you please answer them for me before I leave?</td>
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<td></td>
<td>• Don’t get sidetracked by small talk. Be pleasant but make sure you get meaningful answers to all of your</td>
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<tr>
<td></td>
<td>questions.</td>
<td></td>
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<td></td>
<td>• If you run out of time, make another appointment.</td>
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<tr>
<td>After I’ve seen my doctor, I have a hard</td>
<td>• Repeat what the doctor said back to him/her to be sure you understand.</td>
<td>• Can I tell you what I heard you say, so you can tell me if I heard it right?</td>
</tr>
<tr>
<td>time telling my family what she/he said to</td>
<td>• Write down what you heard.</td>
<td>• Do you have a pamphlet on this problem that I could take home with me?</td>
</tr>
<tr>
<td>me.</td>
<td>• Bring a family member to the appointment if you can.</td>
<td></td>
</tr>
<tr>
<td></td>
<td>• Ask if there is written information you can take home to your family.</td>
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</tr>
<tr>
<td>There is so much about my kidney disease I</td>
<td>• List the things that confuse you.</td>
<td>• Who is the best person on my team to ask about ____________________________?</td>
</tr>
<tr>
<td>don’t understand.</td>
<td>• Ask the social worker to help you find people to answer your questions.</td>
<td>• Do you have anything I could read about ____________________________?</td>
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<td></td>
<td>• Go to the library and do your own research.</td>
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<td></td>
<td>• Join an American Association Kidney Patients or National Kidney Foundation chapter (see below) to learn</td>
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<tr>
<td></td>
<td>from other patients.</td>
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*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?

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**

I've 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 live 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's all in your hands!

—Amy M., Network 15 Patient Advisory Committee Member

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

<table>
<thead>
<tr>
<th>I have the right to:</th>
<th>My job is to:</th>
</tr>
</thead>
<tbody>
<tr>
<td>Be told about my rights and responsibilities</td>
<td>Tell my healthcare team if I don’t understand my medical condition or treatment plan</td>
</tr>
<tr>
<td>Be treated with respect</td>
<td>Treat other patients and staff as I would like to be treated, with respect</td>
</tr>
<tr>
<td>Privacy: My medical records can’t be shared with anyone, unless I say so</td>
<td>Tell my healthcare team if I refuse any treatment or medicine that my doctor has ordered for me</td>
</tr>
<tr>
<td>Dietitian and Social Work services</td>
<td>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</td>
</tr>
<tr>
<td>Be told about my health in a way that I understand</td>
<td>Follow the rules of the dialysis center</td>
</tr>
<tr>
<td>Be told about and choose my treatment options</td>
<td>Get to and from the center for my treatments; I can talk with my social worker if I need help doing this</td>
</tr>
<tr>
<td>Be told about any tests ordered for me and their results</td>
<td>To pay my bills on time; If this is hard for me, I can ask about a payment plan</td>
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<tr>
<td>Be told about the services offered at the center</td>
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<tr>
<td>Be told about the process of dialysis and dialyzer re-use</td>
<td></td>
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<tr>
<td>Be told about any expenses that I have to pay for if they are not covered by insurance or Medicare</td>
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<tr>
<td>Be told about any financial help available to me</td>
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<tr>
<td>Accept or refuse any treatment or medicine my doctor orders for me</td>
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<tr>
<td>Be told about the rules at the treatment center (for example, rules for visitors, eating, and personal conduct)</td>
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<tr>
<td>Choose if I want to be part of any research studies</td>
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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.
DURING THE MEETING:

☐ If not already provided, request your own copy of the POC the other members of the team have already completed.

☐ Check the medications listed on the POC to be sure they are correct.

☐ Review your dialysis treatment prescription lab results (Kt/V, URR), to make sure you are receiving the right amount of treatment for YOU.

☐ Ask the list of questions or address the list of concerns you brought with you.

☐ Ask if other members of the team have concerns related to your POC.

☐ Write your comments on the POC.

☐ Request that any changes in your POC made during the meeting are included prior to your signing the POC and keep a signed copy for your records. You may want to compare this POC to next year’s version.

YOUR QUESTIONS OR CONCERNS:

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To file a grievance about the care you are receiving at your dialysis facility, contact Network 15 at 1.800.783.8818.