Under federal regulations, dialysis patients who have grievances or concerns about the treatment they are receiving at a dialysis unit, have certain rights. Because Medicare is a primary payer of dialysis services, the federal government wants to ensure that patients have rights to speak up about their concerns, and that patients are protected against retaliation or intimidation. The goal is always supposed to be ensuring quality of care.

Under federal regulations, patients have the following rights:

• **The right to know your rights!** You are supposed to be provided with information and education about all of your rights pertaining to dialysis treatment. This should include your rights under federal regulations, as well as your basic patients’ rights.

• **The right to exercise your rights!** In other words, no one should be discouraging, intimidating, or preventing you from exercising your rights, including your right to file a grievance or ask questions about the care you are receiving. You have the right to file a grievance “without restraint or interference and without fear of discrimination or reprisal.”

• **The right to discuss your concerns, grievances, or suggest changes in policies to dialysis unit staff, administration, The Renal Network, and agencies or regulatory bodies with jurisdiction over the facility!** In other words, you have the right to express any concern you have, or any change you would like to suggest, to any staff member or agency involved with the dialysis unit.

**Tip:** If you have a concern or question, it is always best if you can put it in writing, because then dialysis management MUST respond to you. You don’t have to write a long letter and this does not have to be complicated. For example, if you are concerned about a policy stating that no food or drinks are allowed on the unit during dialysis, even for diabetics patients, you could write up a simple grievance like this *(be sure to keep a copy for yourself!)*:

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DATE (always put the date!)

To Dialysis Management,
I would like to know why no food or drink are allowed on the unit, and how this policy affects the health and well-being of diabetic patients. I would like you to reconsider this policy because it is a hardship for many of your patients. I understand that it is my right to receive a written response from you.

Sincerely,

YOUR NAME
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The right to choose your own “patient representative.” In other words, if you are not comfortable speaking up directly or writing up a grievance yourself, you can choose whoever you want to be your “patient representative.” This can be a family member, a trusted friend, an advocate, or even a staff member. The dialysis unit management cannot refuse to hear concerns from your patient representative, as long as that person is behaving appropriately (they are not making threats of physical harm, etc.). Frequently, management staff will say that they can only address the concern if it is brought to them directly by the patient. This is not true – they are obligated under federal regulations to address the concern when it is brought by the “patient representative” – telling someone that they cannot address the concern unless it is brought directly by the patient is a form of restraint and interference, and that is prohibited under federal regulations. Please note that under federal regulations, staff members who act as “patient representatives” should also be protected from reprisal or intimidation.

Here is the federal regulation that protects your rights to file a grievance and to recommend changes in policies and services, and to choose your own patient representative:

"All patients are encouraged and assisted to understand and exercise their rights. Grievances and recommended changes in policies and services may be addressed to facility staff, administration, the network organization, and agencies or regulatory bodies with jurisdiction over the facility, through any representative of the patient's choice, without restraint or interference, and without fear of discrimination or reprisal." 42 CFR 405.2138.

If you have any questions or concerns about these or any other issues, including quality of care, patient health and safety, patients’ rights, or billing and insurance problems, please know that the Champaign County Health Care Consumers (CCHCC) is available to help. We practice confidentiality, which means that we will protect your name and your identity at your request. CCHCC was founded in 1977 and is a community-based non-profit organization.

For more information, please contact:

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