



Network

Consumer News

LARGE PRINT VERSION

Voicing Concerns

People with kidney disease have to cope with care from many different professionals and organizations. At some point, most people find themselves having a concern about their care or how they were treated. It may be very uncomfortable for some to express these concerns.

For kidney patients, discomfort expressing concerns may be due to:

- Concern about being denied dialysis or a transplant
- Fear of being seen as ungrateful
- Lack of confidence in their own knowledge
- General discomfort with confrontation
- Fear of being labeled as a “complainer”
- Cultural customs and communication styles
- Past experiences
- Fatigue
- Feelings of hopelessness

Whatever the reason, patients that do not raise concerns may not receive the care they need and deserve. In some cases, kidney patients may choose to go without needed care instead of raising a concern – for instance, by missing or shortening a dialysis treatment or deciding not to go see their doctor.

Raising a concern with a care provider can be difficult.

The volunteer members of Northwest Renal Network’s Patient Advisory Committee would like to share some tips on how to raise care concerns.

Know Your Rights and Responsibilities

Dialysis centers must inform patients of their rights and responsibilities. Governmental rules provide a list of the minimum rights of all dialysis

patients. For a complete list of your patient rights, contact the Network or request a copy at your dialysis center.

Understand the Grievance Procedure

It is important that you know what to expect and how to raise concerns. Your center is required to notify you of its grievance procedure, notify you of timelines, and respond to your grievance.

Get to Know Your Center's Staff

As a dialysis or transplant patient, you spend a lot of time at the centers and get to know the staff well. These relationships can be supportive and make undergoing treatment a little easier. It can also help you feel more comfortable with raising concerns. Keep in mind that your social worker is available to advocate for you.

Do Not Allow Concerns to Build Up

It is best for you not to allow multiple concerns to build up. By waiting, you may only become more frustrated. It will also make it harder for someone to respond to your concern if the event or problem occurred sometime in the past.

Request a Private Meeting

If you have a concern and can wait, arrange a time to meet with the relevant person or persons rather than raising the concern while that person is busy attending to daily tasks. A private meeting will improve the chances of the person understanding your concern and being able to give it more thought.

Direct Your Concerns to the Correct Person

For instance, if you have a concern about facility policy, the care staff such as nurses and technicians may be able to explain the policy but likely do not have the authority to change anything. Discuss your concern directly with the person able to address it.

It is also important to recognize that care staff must follow company policy and procedures – like all employees.

Write Down Concerns

By writing down your concerns, you will be better prepared to discuss them. It will also give you time to think about why you are concerned.

Start with a Discussion

Avoid starting with requests or expressing a position. Start the conversation with describing the situation, and sharing your reaction, feelings, and observations. Example: “When it happened, it was embarrassing for me.” This helps the other person understand why you are concerned and gives them an opportunity to respond with suggestions and ideas.

Avoid Absolute Statements

Absolute words such as “always” and “never” tend to lead to disagreement. Try to acknowledge positive aspects of your care when you can.

Bring Support

If you feel very anxious or emotional regarding your concern, it may be helpful to ask someone to attend a meeting with you as a support person.

Northwest Renal Network encourages you to try to resolve concerns at your center. However, we understand that it may be difficult at times to do so. We encourage you to contact us if you are unable to resolve a concern or just wish to discuss how to raise a concern about your care.

QUOTES FROM PAC MEMBERS

“Start with asking questions – just posing a question can alert the person to your concern.” “You can make it worse in the heat of the moment.

Let your emotions calm down and then follow-up.”

Roger Gravgaard In-center Hemodialysis Patient

“Try to see the humor in things.” “Research the issue and be persistent.”

Freddie Walker In-center Hemodialysis Patient

“Build relationships, so when you have a problem you feel comfortable raising your concerns.”

Colleen Johnson Transplant Recipient

“Don’t attack the individual.”

“Write down your concerns so you remember them
and discuss them with your social worker.”

Christine Sanders Transplant Recipient

LEARNING POINTS

Governmental rules provide a list of the **minimum rights of all dialysis patients**.

RELATED WEB RESOURCES

Dialysis Facility Compare

www.medicare.gov/dialysis

American Association of Kidney Patients

www.aakp.org/aakp-library/Concern-With-Dialysis-Facility

Kidney School

www.kidneyschool.org

If you would like the information but do not have access to the Internet,
please contact us:

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