



Midwest Kidney Network is a private, nonprofit organization and contractor with the Centers for Medicare & Medicaid Services(CMS).

Our mission is to assess and improve the quality of care provided to people with kidney disease through the following actions.

- Respond to patient concerns about their care
- Help providers improve care and quality of life for dialysis and kidney transplant patients
- Maintain the patient database that supports the national kidney disease program
- Partner with other ESRD Networks, State Survey Agencies, ESRD providers, and organizations helping people with kidney disease



## Transition: Kidney Transplant to Dialysis



Information to help  
**Nephrologists**  
understand and improve  
patient experience



The Midwest Kidney Network Consumer Committee is pleased to present these thoughts on the difficulties many patients face in transitioning from kidney transplant to dialysis.

This is not meant to be an exhaustive presentation of this sensitive topic. It is meant to open up the topic for discussion and future study.

We welcome any observations and experiences you may have on this topic. Please contact Network 11 if you are interested in helping to further this project.

**Midwest Kidney Network  
Consumer Committee  
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## Understanding Patient Perspective

You have just received a patient who has lost a kidney transplant and is transitioning to dialysis. You may be assuming some things.

It is likely that this patient is experiencing a wide range of feelings.

### Fear

*What is going to happen to me?*

*How sick am I going to get?*

*Can I survive this?*

*Should I even go back on dialysis?*

*Will my family survive this?*

*Can I continue to work through this?*

*What if there is nothing we can do?*

*Can I afford this?*

### Guilt

*What did I do wrong?*

*Is this my fault?*

*What will my living donor say or feel?*

*I am such a burden to my family - they don't deserve this.*

### Anger

*Why me?*

*What did I do to deserve this?*

## How Strong Feelings Affect Patients

Strong emotional turmoil can lessen a patient's perception. Patients dealing with these emotions can't remember what was said or instructions that they are given.



Fear can prevent patients from acknowledging the reality of the situation. They may have difficulty effectively advocating for themselves.



Not all patients blocked by fear, guilt, or anger will be easily identified visually. Strong interviewing techniques may be necessary to get through the mask that many patients wear with their physicians.

## How to Help Patients Cope

### Assess Knowledge

Ask patient what their lives were like before their kidney transplant. What worked well for them? What did not work well? What do they know about different treatment options?

### Hear Their Concerns

Patients are often reluctant to discuss their fears or concerns with their families. If you can get the patient to express these concerns, you can identify what areas need more discussion.

### Talk About Options

If there are several treatment options, talk about them up front. This gives hope if one option is failing. If the patient is working with old information, you can show them how treatment options have improved over time.

### Advise Counseling

The trauma of this particular transition may warrant referral to a mental health organization and/or a spiritual advisor. When appropriate, you may be able to provide options for mental health care and/or other support.