



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  
2015**

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



1360 Energy Park Drive  
Suite 200  
Saint Paul, MN 55108

1-800-973-3773  
midwestkidneynetwork.org  
info@nw11.esrd.net

## Transition: Kidney Transplant to Dialysis



**Information to help  
dialysis care providers  
understand and improve  
patient experience**



## 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 about the patient's point of view.

*"They have done this before. They know the ropes." or "They should be able to adapt to the changes in dialysis care."*

These assumptions are not always correct. It is likely that a 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 feel like 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 become hopeless and disinterested in their health.



Feelings can manifest externally and internally. Patients may express aggression, anger, or crankiness. Alternatively, they may become quiet and withdrawn, internalizing their feelings.

## How to Help Patients Cope

### Engage

Do not minimize the patient's experience. Acknowledge it. Encourage them to express their feelings so you can help them find comfort.

*"I can see that you are very upset."*

*"I can understand that this process is overwhelming."*

*"Do you want to talk about how you are feeling?"*

### Inform

Help patients move forward by providing resources and answering questions.

*"What questions can I answer?"*

*"Do you think it would help if you...?"*

*"Have you considered this option?"*

### Empower and Encourage

- Do not underestimate the power of human touch. Holding and stroking a patient's hand can be very comforting,
- Provide patient success stories. Let them know that they are not alone in their experience.
- Help them focus on positive aspects of their life. Ask about things they enjoy.