



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



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## Transition: Kidney Transplant to Dialysis



**Advice for kidney patients  
from kidney patients.**



## Important Points to Remember

The focus of your medical care will depend on who you are seeing.

- **Transplant Team** - if you are working with your transplant team they will be focusing on everything possible to sustain your transplant for as long as possible.
- **Nephrologist Team**- if you are working with your Nephrologist team they will be focusing on preparing you for dialysis

In truth, both focuses are accurate and necessary. But you may need to take the lead by:

Talking with your Transplant Team to make sure that you understand ALL options that are available for you.

Talking with your Nephrologist Team to make sure that you have the most up to date dialysis information, modality choices and that all preparations have been made for a smooth transition.

*“There are new breakthroughs every day and I am currently exploring them with my nephrologist to see what might be appropriate for me. Perhaps there will be an option appropriate for me - perhaps not.”*

## You May Experience a Unique Set of Strong Emotions



### 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 donor say or feel?  
I feel like such a burden to my family*

### Anger

*Why me?  
What did I do to deserve this?*

### Grief

*Denial  
Bargaining  
Depression  
Acceptance*

## How Strong Feelings Affect You

- You may not be able to remember information and instructions.
- You may have difficulty making decisions.
- You may not be able to acknowledge the reality of the situation.



## What can you do?

- Be aware that you may be undergoing strong emotional turmoil during this process
- Understand that you NEED to work with your medical team and advocate for the best possible outcome for your life.
- Talk to your medical team about your emotional state and any needs they can help you meet.
- Speak with other patients who have gone through this same experience. Gain knowledge from their experiences.
- Seek mental/spiritual counseling to help you through this transition