



# Dialysis Patient Depression Toolkit

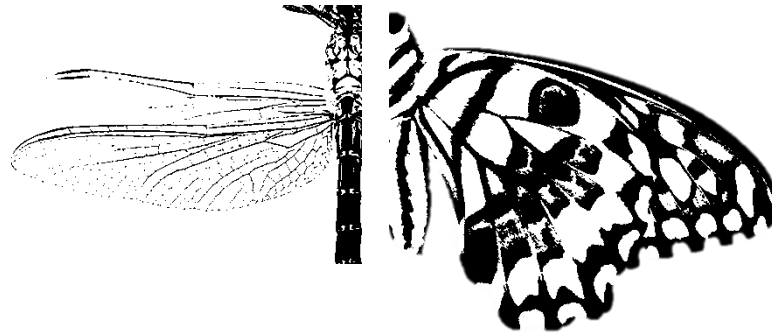
KIDNEY PATIENT  
ADVISORY COUNCIL (KPAC)

THE NATIONAL  
**FORUM**  
OF ESRD NETWORKS

## SYMBOLISM OF DRAGONFLY AND BUTTERFLY

Having flown the earth for 300 million years, dragonflies symbolize our ability to overcome times of hardship. They can remind us to take time to reconnect with our strength, courage and happiness.

Butterflies are deep and powerful representations of life. Around the world, people view the butterfly as representing endurance, change, hope, and life.



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## INTRO

### The Patient's Guide to Dealing with Depression Toolkit

The Forum of End State Renal Disease (ESRD) Network's Kidney Patient Advisory Council (KPAC) has developed the Dialysis Depression Toolkit to help patients who feel they may be experiencing depression. This toolkit was designed **BY patients and FOR patients** but there are important contributions by professional collaborators who graciously joined our workgroup. It is our hope that this toolkit may help explain the complicated topic and how to find help.

The toolkit could be useful for both patients AND facilities. While all facilities are required to screen for depression, there are very few tools available to help a patient move forward after the screening.

This toolkit would not exist without the help, support, and encouragement from the ESRD Forum's Executive Director Advisory Council (EDAC) and the Medical Advisory Council (MAC). These wonderful people have donated time and information toward the creation of this project. Thank you, everyone, for all you have done and continue to do so that we, the patients, can have the best life possible with ESRD.

# CHAPTER ONE

## The Emotional Demands of Dialysis

This chapter will deal with some of the changes that we may face when we deal with dialysis. It will list some of the most common changes. It will provide some patient stories, so we can see how others have dealt with the emotions that resulted from those changes. It is important to remember that we are not alone. Even if we are on dialysis and dealing with anxiety or depression, we can still have loving and productive lives. There are no limits to what we can achieve with determination and the right tools. Many, many people have gone through the same things and we would like to share some of the things that helped us cope.

### REACTIONS TO THE FIRST DIAGNOSIS OF KIDNEY FAILURE

Different people react in different ways. It is safe to say that nobody is happy when they hear that their kidneys are failing, or when they have just started dialysis. Most reactions are a combination of fear, uncertainty and sadness because of the changes in our lives.

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#### FEAR

Fear is one of the most common reactions to loss of kidney function. We may be afraid of the medical system and of the medical process for treatment. We may be afraid of the unknown and of future losses in our lives. And we may be afraid of dying. Fear is most commonly expressed as either anger or depression.

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#### LIFE CHANGES

Many of the changes that we are experiencing are obvious. Others are less obvious. But at some point, we must come to terms with them all.

- **Health Changes**

These are more obvious. Our kidneys are no longer working properly, and we must accept medical interventions to stay alive.

- **Family Dynamics**

These may be less obvious. Our “place” in the family may have changed. We may no longer be the primary source of income or the primary decision maker for our family. Or we may no longer be the one who takes care of everyone else. In fact, others may now have to take care of us.

- **Financial Changes**

Our income may now be reduced, and new bills are coming in. This can drastically change how we have been dealing with our money in the past.

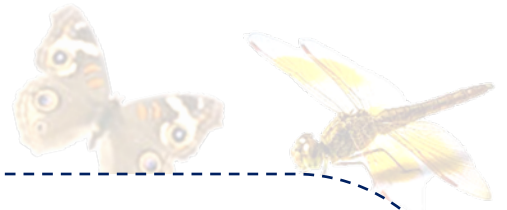
- **Loss Changes**

There may be a lot of losses associated with this change in our lives.

- ✓ Loss of energy – we may be dealing with about half of the energy we had before.
- ✓ Loss of our dreams and plans for our future – nobody grew up wanting to be a dialysis patient. A lot of plans for our future may be on hold or have changed entirely.
- ✓ Loss of control
  - Time – we are now dealing with dialysis schedules and doctor appointments. We have a lot less time for other things.
  - Bodily Functions – we can’t eat or drink like we always have. And we may have vomiting and evacuation issues.
- ✓ Sexuality – issues with performance or libido may need to be dealt with.
- ✓ Hobbies and Activities – a lot of things we have enjoyed in the past may no longer work for us. We may have to adjust or say good-bye to some of the things we loved doing.

All of this can sound very sad. And a lot of it is. But the truth of the matter is, many people have gone through all of this and developed very happy, satisfying lives. In fact, sometimes the new life may be better than the old life.

# Patient Stories



## **Maria**

I was standing behind a lady at the pharmacy and overheard the prescriptions that she was picking up. I knew immediately she was on dialysis because I was also there to pick up my prescriptions for the same reason.

I could hear her crying and as she turned to leave. I asked her if I could speak to her for a minute and she looked at me with tears in her eyes but said nothing. I quickly told her I was a dialysis patient and also a patient advocate. I could see the pain in her eyes.

Maria decided to sit and speak with me for a moment. She told me she was just put on dialysis and was depressed, scared and confused.

We spoke about her new life for about an hour. I suggested she speak to her nephrologist about her depression. I suggested she look into a local support group. She did both. After a month with the support group her depression was much improved and she never took medication for the depression.



## CHAPTER TWO

### Signs of Anxiety and Depression Caused by Overwhelming Stress

Overwhelming stress can cause a lot of damage before we are even aware of it. We often become obsessed with the things we can no longer control. We often find ourselves in a never-ending spiral and don't know how to pull ourselves out of it. Our health and our enjoyment of life are often hurt or lost. We lose hope.

It is very important that we identify this level of stress before damage is done. There are many ways people react to overwhelming stress. They can be divided into three broad categories.

#### EMOTIONAL REACTIONS

Emotional reactions may not always be easy to see, but they impact almost every moment of our lives.

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#### SITUATIONAL STRESS

Situational Stress is an emotional response to a real or perceived threat. It occurs when we think "I have to solve this problem or something bad is going to happen". These types of situations have an ending. We find a solution to the problem and the stress disappears. Situational stress can cause short term health problems.

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#### ANXIETY

Anxiety is a feeling of worry, nervousness, or unease. It is typically about an upcoming event or an unknown outcome. It often results in compulsive behavior or panic attacks. Some signs of Anxiety are:

- **Excessive worry**
- **Sleep problems** – trouble falling asleep or staying asleep or waking up feeling wired with your mind racing without being able to calm yourself down.



- **Irrational fears** – these may not always be obvious. In fact, they may not surface until we face a specific situation and discover we are incapable of overcoming our fear.
- **Muscle tension** – near constant muscle tension like clenching your jaw or balling your fists
- **Chronic indigestion** – Irritable bowel syndrome, constipation and/or diarrhea
- **Self-consciousness**
- **Panic Attacks**
- **Compulsive behaviors** – either mental (like telling ourselves “*It’ll be alright*” over and over again), or physical (like constantly straightening things over and over again).

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## DEPRESSION

Depression is a feeling of deep, deep sadness, despondency, and dejection. It negatively affects how we feel, the way we think, and how we act. It causes feelings of sadness and/or a loss of interest in things we used to enjoy. It is common in dialysis patients and is often a natural reaction to our situation. Some signs of depression are: \*

- **Always feeling sad**
- **Loss of interest** or pleasure in things we once enjoyed
- **Changes in appetite** – weight loss or gain unrelated to dieting
- **Trouble sleeping** or sleeping too much
- **Loss of energy** or increased fatigue
- **Increase in purposeless physical activity** like hand-wringing and pacing or slowed movements and speech
- **Feeling worthless** or guilty
- **Difficulty thinking**, concentrating or making decisions
- **Thoughts of death or suicide**

*\* Please note that some of these signs are also a natural, physical result of dialysis and do not necessarily point to depression. These are only general signs of depression.*

## BEHAVIORAL REACTIONS

Behavioral reactions are often easier to notice. They are often noticed by our family and caregivers.

- **Addiction** – To alcohol, drug, cigarettes, overeating, gambling, etc. This list is endless.
- **Aggression** – This can be minor and temporary, or it can evolve into frequent volatile mood swings. It can be abusive toward others or toward ourselves.
- **Insomnia** – Our thoughts may spiral out of control in the quiet of night.
- **Inability to Stay Awake** – Stress and tension cause our brains to work overtime and may create excessive fatigue, especially during the day.
- **Withdrawal** – Our self-esteem and confidence take a hit. We may no longer believe in our ability to cope with social situations and begin to shut down and isolate.

## PHYSICAL RESPONSES

Many of us don't realize the physical damage that anxiety and depression can cause. Because we are already in a weakened state, this damage can be more severe on us than on those who are not on dialysis. There are a lot of overlapping issues involved with anxiety and depression.

- **Headaches**
- **Muscle Aches** – pain and/or decreased range of motion
- **Bodily Damage**, both internal and external
  - Stomach issues
  - Changes in vision
  - Loss of our ability to breathe naturally
  - Damage to our hearts
  - Damage to our nervous system
  - Damage to our reproductive system
  - Increased risk of certain cancers

# Patient Stories



## William

Patient is a 30 year old 278lb male with falling GFR and rising Creatinine. His physician group has told him to get ready for dialysis. He is not eligible for transplant listing since he is over weight. He has lost 25 pounds since January but still needs to lose another 28 pounds before he can be tested. His medical team put him on steroids nine months ago and he gained over seventy five pounds! The team finally took him off of Prednisone on Monday. This will help him lose the needed weight.

He is frightened and scared about everything that is happening to him. To make matters worse he can not get information from the physician group about his blood type. He has a very large family and many people want to donate. This refusal by the team is causing even more anxiety. He wants to be proactive in finding a donor blood type match.

## James

James was depressed from the time of his diagnosis of ESRD. He continued in a downward spiral for months causing friction within his family of four. He became bitter and mean. His wife and daughters had to leave the family home and find other living arrangements which were difficult because of financial problems caused by ESRD.

James's wife reached out for help for him. He would not talk with us for two months. Finally he reached out to us and we were able to convince him to go to his primary care physician for help. He was prescribed an anti-depression med and received counseling and advocacy from NKF. I am sad to report that it was too late to save the marriage but he now has a wonderful relationship with his ex-wife and children.

## CHAPTER THREE

### Do I Need Help?

A lot of us wonder how well we are coping. We wonder if we need help or if this is as good as it gets. We may not be ready to turn to a professional, but we would like to know whether or not there is something wrong.

#### VALUE OF SELF DIAGNOSTIC TOOLS

A Self Diagnostic Tool is a short, simple test that we can take in the privacy of our own homes. It can help us become more aware of ourselves and help us decide if treatment might be necessary and if a professional assessment is needed. **These tests are NOT a complete diagnosis.** They are simply tools to help us understand what we are feeling.

#### DANGERS OF SELF DIAGNOSTIC TOOLS

These tests are very simple and are only effective if we are completely honest with ourselves when we take them. It is important that we are not being defensive while we take them. We must have enough self-awareness that we can honestly answer the questions. Self-diagnosis will not work if we have a bad opinion of ourselves while we are taking the test. These are just tools to help us understand ourselves and are never meant to replace professional evaluations.

#### DEPRESSION -PHQ 9

This is an easy to use multiple choice self-report inventory that is used as a screening and diagnostic tool for depression. It is one of the most validated tools in mental health and can be a powerful tool to assist with diagnosing depression and anxiety.

**It is important to note that the questions about having little energy and having a poor appetite may not be appropriate for Dialysis Patients. We often have issues in these two areas because of our treatments and not because of depression and anxiety.**

## THE PATIENT HEALTH QUESTIONNAIRE (PHQ-9)

Patient Name: \_\_\_\_\_

Date: \_\_\_\_\_

Over the past 2 weeks, how often have you been bothered by any of the following problems?	Not At all	Several Days	More Than Half the Days	Nearly Every Day
1. Little interest or pleasure in doing things	0	1	2	3
2. Feeling down, depressed or hopeless	0	1	2	3
3. Trouble falling asleep, staying asleep, or sleeping too much	0	1	2	3
4. Feeling tired or having little energy	0	1	2	3
5. Poor appetite or overeating	0	1	2	3
6. Feeling bad about yourself - or that you're a failure or have let yourself or your family down	0	1	2	3
7. Trouble concentrating on things, such as reading the newspaper or watching television	0	1	2	3
8. Moving or speaking so slowly that other people could have noticed. Or, the opposite being so fidgety or restless that you have been moving around a lot more than usual	0	1	2	3
9. Thoughts that you would be better off dead or of hurting yourself in some way	0	1	2	3

Column Totals    \_\_\_\_\_ + \_\_\_\_\_ + \_\_\_\_\_

Add Totals Together \_\_\_\_\_

The scoring is quite simple:

- ✓ All you need to do is add up the columns of 1's, 2's, and 3's and then add them together for a total score.
- ✓ There is no data available specifically for patients with renal disease, but in general, if you scored over a 10, it is considered high and you should follow-up with your social worker, or get a professional assessment.

**\*\* It is also important to get professional help immediately if you score anything other a zero on question 9 regarding hurting yourself.**

## ANXIETY – GAD 7 QUESTIONNAIRE

This is a seven item self-reported questionnaire for the screening of general anxiety. Like the PHQ 9, some of the questions may be affected by the physical outcomes of dialysis. For example, many of us experience restless leg syndrome which is not the same thing as being restless.

<b>Over the last 2 weeks how often have you been bothered by the following problems? (Use “□” to indicate your answer)</b>	<b>Not At all</b>	<b>Several Days</b>	<b>More Than Half the Days</b>	<b>Nearly Every Day</b>
1. Feeling nervous or on edge	0	1	2	3
2. Not being able to stop or control worrying	0	1	2	3
3. Worrying too much about different things	0	1	2	3
4. Trouble relaxing	0	1	2	3
5. Being so restless that it is hard to sit still	0	1	2	3
6. Becoming easily annoyed or irritable	0	1	2	3
7. Feeling afraid as if something awful might happen	0	1	2	3

Column Totals    \_\_\_\_\_ + \_\_\_\_\_ + \_\_\_\_\_ + \_\_\_\_\_

Add Totals Together \_\_\_\_\_

*The GAD-7 is scored the same way as the PHQ-9, just add the columns and then add the sub-totals for a total score. Again, there is no data specific to patient with renal disease, but over a 10 is considered elevated.*

## SLEEPINESS – EPWORTH SLEEPINESS SCALE

The Epworth Sleepiness Scale is widely used in the field of sleep medicine as a measure of a patient’s sleepiness. Scores range from “*it is unlikely that you are abnormally sleepy*” to “*You are excessively sleepy and should consider seeking medical attention.*”

**Remember, though, that dialysis patients are often very tired just after a dialysis treatment. Try to be aware of the difference between fatigue and sleepiness. Fatigue is a general tiredness of the body and mind and is a bit different than the feeling that one gets when they need to sleep. Your answers should be based on the “good” day of your treatment cycle.**

**Choose the most appropriate number for each situation:**

<b>0</b> = no chance of dozing <b>1</b> = slight chance of dozing or sleeping	<b>2</b> = moderate chance of dozing or sleeping <b>3</b> = high chance of dozing or sleeping
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<b>Situation</b>	<b>Chance of Dozing or Sleeping</b>
Sitting and reading	
Watching TV	
Sitting inactive in a public place	
As a passenger in a motor vehicle for an hour or more	
Lying down to rest in the afternoon when circumstances permits	
Sitting and talking to someone	
Sitting quietly after lunch without alcohol	
In a car while stopped for a few minutes in traffic	
<b>Total score (add scores up)</b> (This is your Epworth score)	

*If your Epworth score is over a 10, it may be an indication that you have excessive daytime tiredness, which may be related to the quality of your sleep. Further assessment can help determine the type of sleep disturbance and the recommended treatments.*

## SUBSTANCE ABUSE – CAGE AID

The Cage Aid is widely used as a screening test for problem drinking. The questionnaire takes less than one minute to administer and is meant to find those who drink excessively and need treatment. An answer of 'Yes' to any question below is indication that you may have a problem with substance use and should seek further evaluation.

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Patient Name: \_\_\_\_\_

Date: \_\_\_\_\_

When thinking about drug use, include illegal drug use and the use of prescription drug use other than prescribed.

Questions:	YES	NO
1. Have you ever felt that you ought to cut down on your drinking or drug use?	<input type="checkbox"/>	<input type="checkbox"/>
2. Have people annoyed you by criticizing your drinking or drug use?	<input type="checkbox"/>	<input type="checkbox"/>
3. Have you ever felt bad or guilty about your drinking or drug use?	<input type="checkbox"/>	<input type="checkbox"/>
4. Have you ever had a drink or used drugs first thing in the morning to steady your nerves or to get rid of a hangover?	<input type="checkbox"/>	<input type="checkbox"/>

*Again, these tests are only intended to help us decide if we have an issue that needs further help. They are not a final diagnosis. If they highlight an area of concern, though, then there are steps we can take to confront and resolve the issue.*



## CHAPTER FOUR

### What Type of Help is Out There?

Thankfully, there are a lot of options we can look into if we decide we need help in dealing with the emotional demands of dialysis. Unfortunately, there is no one answer that works for everyone. Several of us have found that a combination of types seems to work best. And even when we find a combination that works, it is likely to change over time and we start looking for a new combination. But peace of mind and a feeling of hope are worth the effort, so we keep fighting for it.

#### ASK QUESTIONS

The more we understand what is happening and what to expect in the future, the more we can let go of the fear. We need to ask our medical team to explain these things in a way that we can understand. We cannot be too shy to ask them to explain things over and over until we understand. We can also ask other patients how they deal with certain situations. They can share their experiences and hope. Often this can be very comforting.

*We must be sure to check our facts with our medical team.*

For those of us who learn by reading, there is a lot of print material available through our units and on the internet. But we must be careful. Not everything that we hear from other patients or read on the internet is accurate.

#### PEER MENTORING

A peer mentor is a patient who is willing to share his or her experience with other patients. Many units have formal Peer Mentoring programs where the social worker will pair up an experienced patient with a patient who is having trouble adjusting. They can listen and share their experiences. Peer mentors do not give medical advice, but they can help us decide what

*They can help decrease our feelings of isolation and help relieve our fears.*

questions we need to ask our medical team. They also help us to better manage our health.

Some units offer Peer Mentoring. Some units do not. Sometimes we can work with a Peer Mentor from a neighboring unit. Several kidney related organizations offer Peer Mentoring through e-mails and through phone calls.

## SUPPORT GROUPS

Support groups can be very helpful in decreasing feelings of isolation and relieving fears. There is something comforting in knowing that the people around us have the same fears and experiences. It is sometimes easier to adjust to living with kidney disease if we do it together.

*Members usually share their experiences and offer one another emotional comfort and moral support.*

Many units have support groups. They may also be available in other units in the area. Or we may need to consider a support group for other forms of chronic illness (like cancer). Some of the experiences may be different, but many of the fears are the same. You should also consider many online forums and social media groups which exist specifically for people dealing with ESRD.

## PERSONAL GOAL SETTING

Sometimes something as simple as having a goal is enough to get us dressed in the morning. These can be one-year goals, one-day goals, or just the next breath. They should be meaningful for us and achievable. Once we have set a goal, we can develop a plan to reach it. Our goals can be changed at any time and new goals can be set.

*They can be as simple as "I want to visit my grandchildren" to "I want to get registered for a transplant".*

## PLAY

Do something fun. If nothing seems fun anymore, keep trying anyway. That's just a symptom of depression. We should plan things we used to enjoy and adapt them to our new limitations. We can also try new things. If some of

our hobbies are more energetic than we can now manage, we can look for new things that are less demanding. Kids play all the time. We should too.

## MEDITATION

Just breathe. Take time to be still and concentrate on breathing. There is a form of meditation called Mindfulness that helps us slow down the chatter in our brains and just breathe. It helps us to stop replaying old conversations over and over again. It helps us stop inventing conversations that haven't even happened yet. There are several free apps available for phones and iPads that can help us learn how to calm down and breathe.

## RELIGION/SPIRITUALITY

Many of us hold on to or turn to our faith. Pastoral counseling can help to ease our fears and restore our peace of mind.

There are several ways to turn to Faith, Religion and Spirituality.

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### SEEK OUT A QUALIFIED PASTOR OR FAITH COUNSELOR

Talking to a faith-based professional may help us get a better perspective on our depression or anxiety.

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### GET INVOLVED IN WORSHIP SERVICES

By attending worship services, we may find a support group to help with overcoming depression and anxiety.

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### SPIRITUALITY CLASSES

Seeing and hearing what scripture has to say on certain topics may help us cope with the problems that we face from time to time.

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### SERVICE

Helping others may make us feel good and puts our focus on others' needs.

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### MUSIC

Inspirational music and other forms of music help lift our spirits. Listening to music throughout the day may do wonders.

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## PRAYER AND MEDITATION

Talking with your Creator or spiritual guide, and mediating on their words and teachings can provide comfort and strength.

## EXERCISE

Exercise can be a healthy coping strategy. It releases feel-good endorphins and can break the worry cycle. We can gain confidence by meeting small exercise goals and it may help us find healthy social interactions.

## 12 – STEP PROGRAMS

If there is a leaning toward self-medication or substance abuse, 12-step programs have a long history of success. While they may not work for everyone in every situation, many people have found solid coping skills through the 12 steps. Alcoholics Anonymous is the most easily recognized of the 12-step programs, but there are programs out there for a variety of compulsive behaviors ranging from food compulsions to gambling.

## PSYCHOTHERAPY

Psychotherapy is another name for talk therapy and there is a wide variety in the types of providers and styles that use psychotherapy. More is discussed in the following chapter (Chapter 5), but there is strong evidence that psychotherapy helps address most mental health issues. There is even growing evidence that it works well for patients with kidney disease.

## PHARMACEUTICAL OPTIONS

Any physician can prescribe medication designed to reduce depression or anxiety, but a psychiatrist is a specialist in this area. There are many medications that are relatively safe and have few side effects that can help and are considered safe to be used in patients with compromised renal function. You may want to start the conversation with your primary care doctor or nephrologist, or you can ask for a referral.

## CHAPTER FIVE

### Picking a Treatment Provider and How to Prepare for a Mental Health Visit

Once you have decided that it is time to go see a professional, there are some things that you should consider to make sure you get the most out of the experience. It is important to know that once you have decided what type of provider you would like to see, you may need a referral from either your nephrologist or your Primary Care Physician.

#### SELECTING THE RIGHT MENTAL HEALTH PROFESSIONAL FOR YOU

Being a skilled mental health provider is both a science and an art, so picking someone you can work with and feel comfortable with is just as important as picking someone with appropriate training and expertise.

#### CLARIFYING YOUR GOALS FOR TREATMENT

The first step in the process of picking the right provider is knowing your goals for treatment.

- Do you want someone to work on a specific issue you are having?
- Would you like someone that you can talk to about the things going on in your day-to-day life?
- Do you want someone who will use a structured, focused approach or someone who will allow the treatment to run its natural course?
- Are you looking for short-term treatment or someone who will be available to you over the next months and years?

#### DIFFERENT DEGREES

There is a wide array of provider choices for people looking for mental health treatment. The titles and degrees vary a bit state by state, but here is an overview of the types of providers available. Keep in mind, though, that your

unit Social Worker is an incredible resource with knowledge on local and national providers. This is a good place to start.

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#### PEER MENTORING

Someone with limited formal training, but often has similar life experiences to the groups they work with.

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#### BACHELOR LEVEL CLINICIANS

Someone with a college degree in counseling. Some states have a license for this level clinician while other states require a master's degree to treat patients. Some substance abuse counselors are bachelor level clinicians.

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#### MASTER'S LEVEL CLINICIANS/MASTER'S IN SOCIAL WORK

Requires post graduate training and supervised clinical experience. Clinicians employed at dialysis centers are often master's level clinicians, as are many couples counselors.

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#### PSYCHOLOGIST

Doctoral level clinician. In most states these cannot prescribe medication, but are experts in psychotherapy

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#### PSYCHIATRIST

Went to medical school and then did a residency in psychiatry. They prescribe medication and often combine pharmacology with psychotherapy.

### DIFFERENT ORIENTATIONS

In picking a provider it is often helpful to understand his or her professional orientation (model in which they treat patients) to help determine if it will be a good fit for your particular goals.

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#### SUPPORTIVE PSYCHOTHERAPY

This type of treatment is unstructured and is designed to help the patient feel heard and supported. The therapist usually does not have his or her own agenda, but lets the patient focus the session.

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### PSYCHODYNAMIC PSYCHOTHERAPY

Originally based on the work of Freud, modern psychodynamic psychotherapy often uses unstructured sessions to help the patient become aware of conflicts and patterns in their life.

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### COGNITIVE BEHAVIORAL THERAPY

Highly structured, symptom focused treatment. This has the largest evidence base supporting it, but can be quite challenging work, as the therapist will often have a loose agenda for each session to help the patient reach his or her goal.

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### ECLECTIC PSYCHOTHERAPY

This is the term therapists use when they don't practice strictly in one orientation, but combine different techniques depending on the needs of the patient.

## COMMON BARRIERS TO SUCCESSFUL THERAPY

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### COST

Can vary widely depending on where you live and the degree of the practitioner you choose. Many mental health professionals accept insurance but many do not accept any insurance at their practice, and the patient pays out of pocket for each session.

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### TIME

Sessions are usually 30 or 45 minutes long and are commonly once a week, so make sure you budget enough time to devote to treatment.

“Short term treatment” usually runs about 12 sessions (3 months) and some types of therapy do not have a predetermined length.

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### CONVENIENCE

Getting renal replacement therapy is extremely demanding in many ways, including time, energy and cost. For mental health treatment to work, it is important to pick a modality that does not add too much additional burden. If quality mental health providers are not readily available where you live, you may want to consider having your sessions chair-side, over the phone, or through video-conference.

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### THERAPIST KNOWLEDGE OF ESRD

Many people, including therapists, know very little about renal disease and its demands. Depending on the nature of your issue, the importance of the therapist having some appreciation of ESRD will vary.

## PREPARING FOR YOUR MENTAL HEALTH VISIT

Some people have some anxiety about going to see a mental health professional. While there are many differences in how various practices are organized (as an example, a group clinic is quite different than a private practice), there are some things that most mental health professionals will have in common.

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### DIFFERENCE BETWEEN INTAKE AND THERAPY

The first session or two with a new provider is often spent getting background information. This may be quite different than the usual therapy sessions once formal treatment has begun. So it is difficult to get a sense of what treatment will be like with a particular provider from the first sessions.

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### COMMON QUESTIONS A THERAPIST MAY ASK

Chief complaint - People often have long and complicated life stories, so mental health providers will usually want to know what the main



problem that you are experiencing now is. They may ask *“What brings you in today?”* or some other similar question as an opening question.

Providers will often ask questions about your mental health treatment history such as:

- Have you been in treatment before?
- What kind?
- For what?

They may also ask some general questions about your medical health and any major health problems you are experiencing. There may be questions about:

- your developmental history
- your childhood
- your education

Finally, some mental health practitioners ask questions about:

- Your “mental status”
- A brief overview of your memory attention and other cognitive abilities.

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#### SOME QUESTIONS YOU MAY WANT TO ASK A POTENTIAL MENTAL HEALTH PROVIDER

- It is your right to know the exact cost of each session and what portion, if any, your insurance will cover.
- It is prudent to know what type of license they have, where they went to school and how long they have been in practice.
- It is very reasonable to ask the provider about their experience treating people with similar problems to the one you are seeking help for.
- How long do people usually stay in treatment? What can I expect from treatment?
- What information is shared with your physician and how often will they be in communication with your health care team?

# Patient Stories



## Larry

Larry was working about eighty miles from home when his kidneys failed with no warning. He was admitted to a hospital through the emergency room. He was far from home and alone. Once his labs were reviewed it was determined he needed to be on dialysis NOW! In the course of three hours his entire world changed. Depression and fear started quickly. His future was no longer controlled by him.

After the first week or so he was told this may be an acute episode. This did raise his spirits a bit. Unfortunately this turned out not to be the case and his diagnosis was changed to ESRD. He was the sole support of his family. He was an over the road truck driver and basically ESRD prohibited this from continuing.

It did take us months to deliver the solutions he needed to get through this ordeal. We made sure he was given all the answers to the questions he had. He received disability payments. He is now part of a Kidney Support Group and doing much better. He is seeing a psychologist on a regular basis and his depression is in check.

# PREPARING FOR A MENTAL HEALTH VISIT

## Worksheet

- ◆ My primary goal for treatment is (feel less depressed, get better sleep, to drink less, etc.)

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- ◆ Consider the factors that are most important to you in a provider (expertise, cost, age, orientation, convenience, etc.)

The qualities that are most important to me in a provider to develop a positive working relationship are:

1. \_\_\_\_\_

2. \_\_\_\_\_

3. \_\_\_\_\_

### **Be prepared to share the following with your practitioner:**

- ◆ The primary reason I am going to treatment today is because I would like help with

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- ◆ Briefly describe how long this problem has been going on:

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- ◆ Briefly describe how this problem is affecting you (how severe is it):

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- ◆ Briefly describe some of the things you have already tried to address the problem:

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- ◆ If you have any ideas about what you would like to try (or are not willing to try) that may help, list them here:

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## INFORMATION FOR PROFESSIONALS

### A Guide for Mental Health Providers Seeing a Patient with End Stage Renal Disease

#### WHAT IS END STAGE RENAL DISEASE (ESRD)?

If there is damage to the kidneys and there is a decreased ability to filter out toxins, this is called Chronic Kidney Disease (CKD). Millions of people in this country have the earlier stages of CKD. If kidney function drops to around 10%, this is referred to as End Stage Renal Disease (ESRD). Once the kidneys fail, patients need renal replacement therapy or they will not be able to live. The main causes for CKD in this country are diabetes and high blood pressure. Life expectancy is somewhat shortened for people with ESRD, but depending on the age at diagnosis, many people live for a long time while receiving renal replacement therapy.

#### HOW IS ESRD TREATED?

The ideal treatment for ESRD is a kidney transplant, but due to the shortage of donated kidneys the great majority of patients requiring renal replacement therapy are receiving hemodialysis. While other forms of dialysis are increasing in popularity the majority of the dialysis population in the USA is on in-center hemodialysis. Hemodialysis involves the artificial filtration of the blood through a machine. This process typically takes about 4 hours and is done 3 times a week in specialty hemodialysis centers.

#### WHAT ARE THE SPECIAL CHALLENGES A PATIENT MAY BE EXPERIENCING?

Clearly the dialysis treatment is quite demanding, often leaving the patient totally fatigued. Depression is very prevalent and anxiety is quite common as well. There is a restrictive diet and severe fluid restriction requirements for people on dialysis. The demands of the illness and its treatment are very high, and consequently compliance may be an issue. As with other demanding

chronic medical conditions there are often associated changes to social role, family dynamics and financial status. Patients with ESRD are at higher risk for sleep disturbance and may have pain associated with their condition. All of these challenges are placed on top of the usual demands of regular living. ESRD has a higher rate of comorbid depression than other chronic medical conditions.

### WHAT TYPES OF MENTAL HEALTH TREATMENTS WORK?

There is limited data available specific to ESRD because psychiatric clinical trials usually exclude patients with ESRD. Unfortunately, data regarding the effectiveness and safety of psychotherapeutic agents in ESRD patients is also limited. A number of medications, such as tricyclic antidepressants, have resulted in adverse effects that need to be avoided. All psychotherapeutic medications should be started at low doses and increased carefully while being closely monitored. It is critically important to collaborate with the patient's nephrologist to tailor the appropriate therapy to address the needs of the patient.

### SUGGESTIONS FOR WORKING WITH PEOPLE WHO HAVE COMORBID ESRD

Treatment burden is a major issue. Having additional outpatient appointments can be overwhelming for many dialysis patients, consider non-conventional modalities to supplement sessions in the event of exhaustion, dialysis schedule change or illness. Be mindful that the individual experience of ESRD is quite varied and that the additional burden imposed by the medical condition may be only peripherally related to the presenting mental health issue.

## PATIENT RESOURCES

### Where can I get more information?

- American Society of Nephrology  
<https://www.asn-online.org/>
- The National Kidney Foundation  
<https://www.kidney.org/>
- Your Unit Social Worker

### IMMEDIATE HELP

- **Mental Health.gov**  
Get immediate help!  
<https://www.mentalhealth.gov/get-help/immediate-help>
- **National Alliance of Mental Illness**  
800-950-6264 ♦ <https://www.nami.org/>
- **Suicide Prevention Lifeline**  
1-800-273-TALK (8255) ♦ <http://www.suicidepreventionlifeline.org>  
24-hour, toll-free, confidential suicide prevention hotline available to anyone in suicidal crisis or emotional distress.  
  
Your call is routed to the nearest crisis center in the national network of more than 150 crisis centers.

### ASK QUESTIONS

- **American Association of Kidney Patients**  
1-800-749-AAKP ♦ <https://aakp.org/dialysis-education/>
- **DaVita – Kidney Care**  
1-800-244-0680 ♦ <https://www.davita.com/kidney-disease>
- **Dialysis Clinic, Inc – DCI**  
1-615-37-3061 ♦ <http://www.dciinc.org/articles/>

- **ESRD National Coordinating Center**  
844-472-4250 ♦ <https://www.esrdncc.org/en/resources/>
- **Fresenius – Kidney Care**  
1-800-377-4607 ♦ <https://www.freseniuskidneycare.com/>
- **Kidney School**  
Kidney School is a comprehensive online education program for people who want to learn how to manage and live with chronic kidney disease  
<http://www.kidneyschool.org/mods/>
- **National Kidney Foundation**  
1-855-NKF.CARES (653-2273) ♦  
<https://www.kidney.org/kidneydisease>
- **Life Options**  
Life Options is a program of research, research-based education, and outreach founded in 1993 to help people live long and live well with chronic kidney disease  
<https://lifeoptions.org/>

## PEER MENTORING

- **ESRD National Coordinating Center**  
Peer Mentoring Resources  
<http://esrdncc.org/patients/educational-materials/>
- **ESRD Network 5**  
Peer Up! Program - A Special Innovation Project  
<http://www.esrdnet5.org/Special-Initiatives/Peer-Up!-Program.aspx>
- **ESRD Network 10**  
The Renal Network Facility Peer Program  
[http://www.therenalnetwork.org/services/facility\\_peer\\_program.html](http://www.therenalnetwork.org/services/facility_peer_program.html)
- **ESRD Network 11**  
Midwest Kidney Network Peer Mentoring Coaching Materials  
<http://midwestkidneynetwork.org/engaging-patients/peer-mentoring>

- **ESRD Network 16**

Northwest Renal Network brief guide to peer mentoring

<https://nwrn.org/images/LAN2015/PeerMentoring.pdf>

- **National Kidney Foundation**

NKF Peers Contact

855-653-7337 ♦ <https://www.kidney.org/patients/peers>

Speak with a trained peer mentor who can share their experiences about dialysis or transplant.

## SUPPORT GROUPS

- **American Association of Kidney Patients – AAKP**

Find a Support Group – by State

800-749-AAKP ♦ <https://aakp.org/support-groups/>

This site will help you find support groups in your area. Remember, though, that Cancer Support groups may also be helpful. Many of the issues are similar.

- **DaVita Kidney Care: Kidney Disease and Dialysis Forums**

<http://forums.davita.com/>

## MEDITATION

- **Calm**

Reduce Anxiety, sleep better, live happier. Calm brings clarity, joy and peace to your daily life. Join the millions experiencing the life-changing benefits of meditation and mindfulness

<https://www.calm.com/>

- **Mindful**

Mindfulness meditation practice couldn't be simpler: take a good seat, pay attention to the breath, and when your attention wanders, return. By following these simple steps, you can get to know yourself up close and personal.

<https://www.mindful.org/mindfulness-how-to-do-it/>

- **UCLA Health: Free guided meditations**

<http://marc.ucla.edu/mindful-meditations>



## EXERCISE

- **DaVita:** Exercise for Dialysis Patients  
<https://www.davita.com/kidney-disease/dialysis/life-on-dialysis/exercise-for-dialysis-patients/e/5295>
- **Fresenius Kidney Care:** Make Exercise a part of your every day  
<https://www.freseniuskidneycare.com/thriving-on-dialysis/staying-healthy/exercise>
- **Life Options:** A guide for people on dialysis  
<https://lifeoptions.org/assets/pdfs/exercise.pdf>

## 12 – STEP PROGRAMS

- **Alcoholics Anonymous**  
Find a meeting near you  
[https://www.aa.org/pages/en\\_US/find-aa-resources?zipcode=Zip%2FPostal+Code&csrf=f3ec3a6089fb91c7362cd0b614bcbb15741fdcf6e384d4f10517797f9fbc8b08](https://www.aa.org/pages/en_US/find-aa-resources?zipcode=Zip%2FPostal+Code&csrf=f3ec3a6089fb91c7362cd0b614bcbb15741fdcf6e384d4f10517797f9fbc8b08)
- **Behavioral Health Treatment Services Locator**  
Find alcohol, drug, or mental health treatment facilities and programs around the country.  
<https://findtreatment.samhsa.gov>
- **Opioid Treatment Program Directory**  
Find treatment programs in your state that treat addiction and dependence on opioids, such as heroin or prescription pain relievers.  
<http://dpt2.samhsa.gov/treatment>
- **Recovery.org**  
Tap into a community of people in recovery, people seeking help with an addiction, and those seeking help for a loved one... Join our community forums for free today!  
<https://www.recovery.org/forums/>

- **Substance Abuse and Mental Health Services Administration**  
1-800-622-HELP (4357) ♦ <https://www.samhsa.gov/find-help>  
Also known as, the Treatment Referral Routing Service, this Helpline provides 24-hour free and confidential treatment referral and information about mental and/or substance use disorders, prevention, and recovery in English and Spanish.

## PSYCHOTHERAPY

- **American Psychology Association**  
Psychologist Locator  
[https://locator.apa.org/?\\_ga=2.75654108.896303003.1523214805-782561789.1523214805](https://locator.apa.org/?_ga=2.75654108.896303003.1523214805-782561789.1523214805)
- **American Psychiatric Association - psychiatrist finder**  
<http://finder.psychiatry.org/>
- **Good Therapy**  
Find the Right Therapist  
<https://www.goodtherapy.org/find-therapist.html>
- **Psychology Today**  
Find a therapist  
<https://www.psychologytoday.com/us/therapists>

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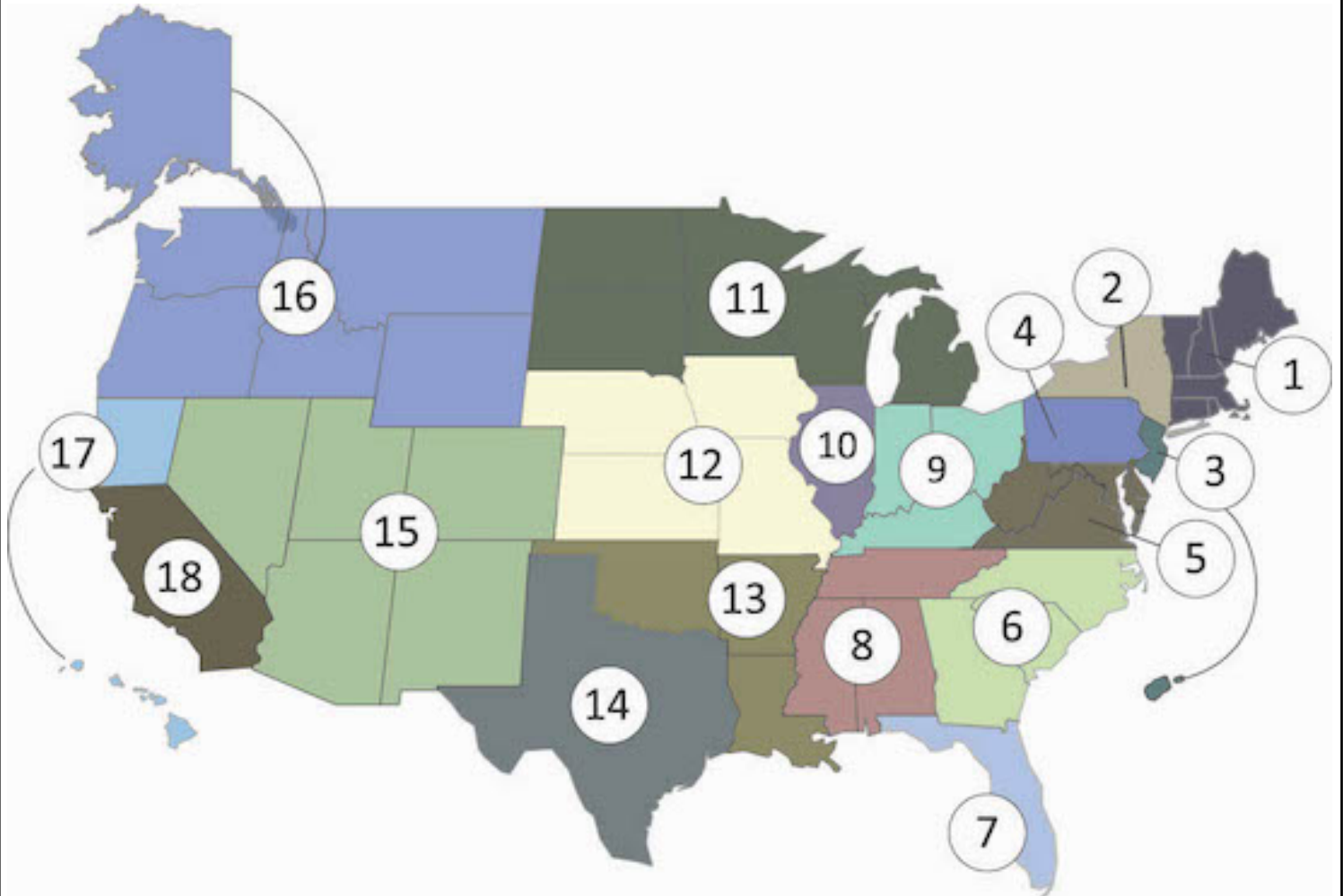
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## ESRD NETWORKS' PATIENT TOLL FREE NUMBERS/MAP

	<b>State(s) Covered</b>	<b>Patient Toll Free Telephone #</b>
<b>Network 1</b>	CT, MA, ME, NH, RI, VT	(866) 286-3773
<b>Network 2</b>	NY	(800) 238-3773
<b>Network 3</b>	NJ, PR, US VI	(888) 877-8400
<b>Network 4</b>	DE, PA	(800) 548-9205
<b>Network 5</b>	DC, MD, VA, WV	(866) 651-6272
<b>Network 6</b>	GA, NC, SC	(800) 524-7139
<b>Network 7</b>	FL	(800) 826-3773
<b>Network 8</b>	AL, MS, TN	(877) 936-9260
<b>Network 9</b>	IN, KY, OH	(844) 819-3010
<b>Network 10</b>	IL	(800) 456-6919
<b>Network 11</b>	MI, MN, ND, SD, WI	(800) 973-3773
<b>Network 12</b>	IA, KS, MO, NE	(800) 444-9965
<b>Network 13</b>	AR, LA, OK	(800) 472-8664
<b>Network 14</b>	TX	(877) 886-4435
<b>Network 15</b>	AZ, CO, NM, NV, UT, WY	(800) 783-8818
<b>Network 16</b>	AK, ID, MT, OR, WA	(800) 262-1514
<b>Network 17</b>	AS, GU, HI, MP, N. CA	(800) 232-3773
<b>Network 18</b>	S. CA	(800) 637-4767

You may visit the ESRD National Coordinating Center (NCC) website <https://esrdncc.org/en/ESRD-network-map/> for your ESRD Network's information and resources in your state or region.



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