

# Depression & Dialysis: Removing the Stigma & Strengthening our Mental Health

Tools and resources From patients For patients to help us cope

**October 4, 2018** 



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Chair, Forum of ESRD Network's Kidney Patient Advisory Council (KPAC) & Chair, HSAG ESRD Network 17 Patient Advisory Council (PAC)



# Webinar Planning Committee

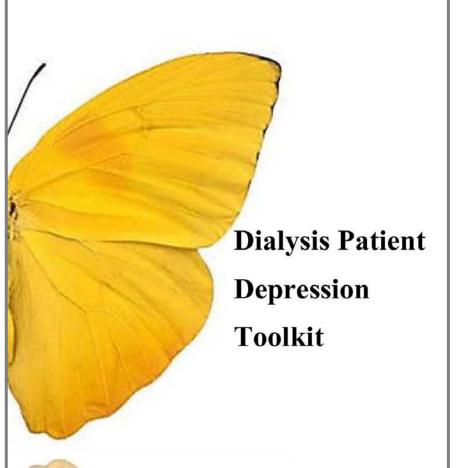


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# **The Depression Toolkit**





- Written BY Patients
   FOR Patients
- Spanish version available soon
- View, download and print free of charge from the Forum website:

http://esrdnetworks.org/re sources/toolkits/patienttoolkits



KIDNEY PATIENT Advisory council (KPAC)





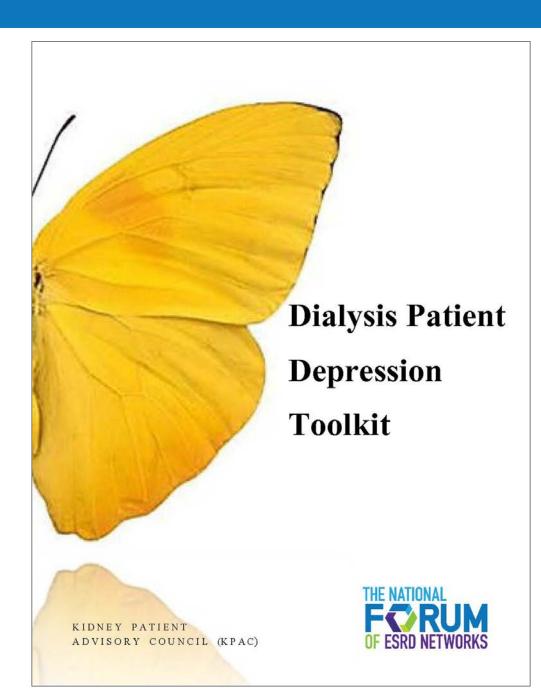
# **One Patient's Experience**

# **Derek Forfang** Chair, Forum's Kidney Patient Advisory Council



# The Depression Toolkit: A Brief Overview

# **Kaggie Carey** Member, Forum's Kidney Patient Advisory Council PAC Chair, Midwest Kidney Network







By Patients For Patients But Applicable for Everyone

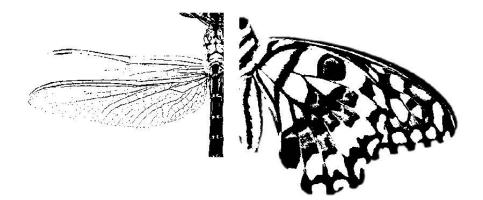
Developed for Patients to Use BUT . . .



#### 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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#### **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
  - o Changes in vision
  - Loss of our ability to breathe naturally
  - Damage to our hearts
  - Damage to our nervous system
  - o Damage to our reproductive system
  - o 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)

1		Every Day
	2	3
1	2	3
1	2	3
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1	2	3
1	2	3
1	2	3
1	2	3
1	2	3
	++	
ner		
vith renal di		general, i
diately if		uthing
	should follo	vith renal disease, but in should follow-up with you score an arself.



#### 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 modical team to

explain these things in a way th to ask them to explain things or ask other patients how they de experiences and hope. Often th

We must be sure<br/>to check our facts<br/>with our medical<br/>team.For the<br/>print n<br/>internet<br/>that we<br/>internet

#### PEER MENTORING

A peer mentor is a patient who her experience with other patie formal Peer Mentoring prograr worker will pair up an experier patient who is having trouble a and share their experiences. P medical advice, but they can he our hobbies are more energetic than we can now manage, we new things that are less demanding. Kids play all the time. W

#### MEDITATION

Just breathe. Take time to be still and concentrate on breathi form of meditation called Mindfulness that helps us slow dow our brains and just breathe. It helps us to stop replaying old over and over again. It helps us stop inventing conversations even happened yet. There are several free Aps available for p 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 counselin ease our fears and restore our peace of mind.

There are several ways to turn to Faith, Religion and Spiritua

#### SEEK OUT A QUALIFIED PASTOR OR FAITH COUNCILOR

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

#### GET INVOLVED IN WORHIP SERVICES

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

#### 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.

#### SERVICE

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

#### 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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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.

#### PERSONAL GOAL SETTING

You sh

social 1

people

Sometimes something as simplies enough to get us dressed in the can be one-year goals, one-day next breath. They should be mand achievable. Once we have a develop a plan to reach it. Our changed at any time and new get.

#### PLAY

Do something fun. If nothing se just a symptom of depression. adapt them to our new limitation

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 afficient between the form of the superior.

#### 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.

#### 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 they 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 of diagnosis, many people live for a long time while receiving renal replacement therapy.

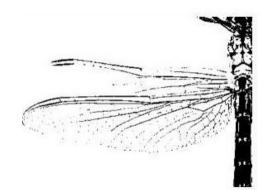
#### HOW IS ESRD TREATED?

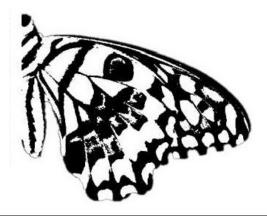
The ideal treatment for ESRD is a kidney transplant, but due to the shortage of donated kidneys the great majority of patients requiring renal replacement therapy are receiving hemodialysis. While other forms of dialysis are increasing in popularity the preponderance of the dialysis population in the 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

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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 nonconventional 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 <u>https://www.asn-online.org/</u>
- The National Kidney Foundation https://www.kidney.org/
- Your Unit Social Worker:

Social workers in dialysis clinics are required to have a master's degree in social work and are trained mental health counselors. Seeking mental health help from your dialysis social worker is one option, but if you would like to seek help outside the dialysis unit, your social worker can refer you to other resources.

#### **IMMEDIATE HELP**

Mental Health.gov
 Get immediate help!
 https://www.mentalhealth.gov/get-help/immediate-help

- National Alliance of Mental Illness 800-950-6264 \* <u>https://www.nami.org/</u>
- Suicide Prevention Lifeline

1-800-273-TALK (8255) • <u>http://www.suicidepreventionlifeline.org</u> 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 \* <u>http://www.dciinc.org/articles/</u>
- ESRD National Coordinating Center 844-472-4250 \* <u>https://www.esrdncc.org/en/resources/</u>
- Fresenius Kidney Care
   1-800-377-4607 \* <a href="https://www.freseniuskidneycare.com/">https://www.freseniuskidneycare.com/</a>
- Kidney Fund <u>http://www.kidneyfund.org/training/webinars/archive.html</u>
- 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 <a href="http://www.kidneyschool.org/mods/">http://www.kidneyschool.org/mods/</a>

- 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 <a href="https://lifeoptions.org/">https://lifeoptions.org/</a>

 Renal Support Network HOPEline 800-579-1970 https://www.rsnhope.org/hopeline-kidnev-disease-support-phone-line/



#### PEER MENTORING

- ESRD National Coordinating Center Peer Mentoring Resources <u>http://esrdncc.org/patients/educational-materials/</u>
- ESRD Network 5
   Peer Up! Program A Special Innovation Project
   <u>http://www.esrdnet5.org/Special-Initiatives/Peer-Up!-Program.aspx</u>
- ESRD Network 10
   The Renal Network Facility Peer Program
   http://www.therenalnetwork.org/services/facility peer program.html
- ESRD Network 11
   Midwest Kidney Network Peer Mentoring Coaching Materials
   <u>http://midwestkidneynetwork.org/engaging-patients/peer-mentoring</u>
- 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 \* <u>https://www.kidney.org/patients/peers</u>
   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 \* <a href="https://aakp.org/support-groups/">https://aakp.org/support-groups/</a>
   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 <u>http://forums.davita.com/</u>

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

#### EXERCISE

- DaVita: Exercise for Dialysis Patients https://www.davita.com/kidney-disease/dialysis/life-ondialysis/exercise-for-dialysis-patients/e/5295
- Fresenius Kidney Care: Make Exercise a part of your every day <u>https://www.freseniuskidneycare.com/thriving-on-dialysis/staying-healthy/exercise</u>
- 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
 <u>https://www.aa.org/pages/en\_US/find-aa resources?zipcode=Zip%2FPostal+Code& csrf=f3ec3a6089fb91c7362c
 <u>d0b614bcbb15741fdcf6e384d4f10517797f9fbc8b08</u>

</u>



 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) \* <u>https://www.samhsa.gov/find-help</u>
 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
   <u>https://locator.apa.org/? ga=2.75654108.896303003.11</u>

   782561789.1523214805
- American Psychiatric Association psychiatrist finde http://finder.psychiatry.org/
- Good Therapy Find the Right Therapist <u>https://www.goodtherapy.org/find-therapist.html</u>
- Psychology Today

Find a therapist <a href="https://www.psychologytoday.com/us/therapists">https://www.psychologytoday.com/us/therapists</a>





NKF 2018 Kidney Care Strategies Symposium

> Search Site only in current se

### **Forum Website:**

### esrdnetworks.org

http://esrdnetworks.org/res ources/toolkits/patienttoolkits



Advocating for the organizations that monitor the quality ( chronic kidney disease, dialysis and kidney transplant care in

lome	About Us Membership Resources & News Education Conta	act Us	
Depr	are here: Home / Resources & News / Toolkils - New Look, Same Great Content! / Patient Toolkils / I ression Tookkit - English Dialysis Patient Depression Toolkit -		News Quality Conference - In t News Jul 13, 2016
	Title	Туре	Partnership for Patients
	Dialysis Patient Depression Toolkit - English (complete toolkit - 38 pages)	File	Jul 13, 2016
	Chapter 1: The Emotional Demands of Dialysis (3 pages)	File	More news
	Chapter 2: Signs of Anxiety and Depression Cuased by Overwhelming Stress (4 pages)	File	MOIC DOWS
1.1	Chapter 3: Do I Need Help (5 pages)	File	Upcoming Events
	Chapter 4: What Type of Help is Out There (4 pages)	File	Summer BOD Meeting
1.6	Chapter 5: Picking a Treatment Provider and How to Prepare for a Mental Health Visit (7 pages)	File	Aug 24, 2018 - Aug 25, 20 Chicago, IL
	Appendix: Information for Professionals (2 pages)	File	
1.6	Appendix: Patient Resources (5 pages)	File	NKF Council on Renal Nutrition (Upstate & Wes
			NY)



**American Association** of Kidney Patients Lisa Garner **AAKP Board Member Erin Kahle Director, Stakeholder Operations** 



# MISSION

## THE INDEPENDENT VOICE OF KIDNEY PATIENTS SINCE 1969™

The American Association of Kidney Patients is dedicated to improving the quality of life for kidney patients through education, advocacy, patient engagement and the fostering of patient communities.

**Founded by Patients for Patients** 



# **CORNERSTONES OF AAKP**

**EDUCATION** 



## ADVOCACY



Advocate







**ENGAGEMENT** 

# GUIDE TO OUR SUPPORT RESOURCES

## Brochures

- Understanding Depression in Kidney Disease (PDF)
- When a Loved One is Depressed (PDF)
- https://aakp.org/shop/

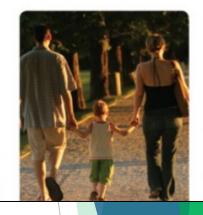
## Articles and Videos

- Depression: The Struggle is Real
- Coping with Kidney Disease
- Coping with a Chronic Illness: Sharing the Diagnosis and Finding Support
- https://aakp.org/aakp-healthline/
- aakpRENALIFE Magazine and E-newsletters
  - https://aakp.org/magazine/
- Blog
  - https://aakp.org/aakp-blog/



#### When Your Loved One Is Depressed

Tips on How You Can Help



UNDERSTANDING DEPRESSION IN KIDNEY DISEASE



Listen. Learn. Live. 🕝

# SUPPORT RESOURCES, cont'd

Support Groups by state
 <u>https://aakp.org/support-groups/</u>

AAKP Ambassador Program
 95+ patients, caregivers, and living

donors representing 47 states plus Washington, DC

<u>https://aakp.org/fellow-patients/</u>





# JOIN US

Free Patient/Family Member Membership www.aakp.org ▶ info@aakp.org ▶ (800) 749-2257 ▶ Follow us on social media! facebook.com/kidneypatient twitter.com/KidneyPatients instagram.com/kidneypatients pinterest.com/kidneypatients



Erin Kahle Director, Stakeholder Operations 813-400-2393 ekahle@aakp.org



# National Kidney Foundation

**Curtis Warfield** NKF Peer Mentor

Kelli Collins, MSW Vice President, Patient Engagement



# NKF.PEERS

- National, telephone-based peer support program.
- Support with:
  - Stage 4 chronic kidney disease
  - Dialysis
  - Kidney transplant
  - Living donation

97%

would recommendNKF Peers to someone ina similar situation.

# National Kidney Foundation: Resources & Support Programs

- NKF Peers
- NKF Cares Helpline
- Educational Information & Patient Stories
- Online Communities

# NKF Cares®

Patient Information Help Line | 855.NKF.CARES

• National toll-free Help Line

1-855-653-2273 <u>nkfcares@kidney.org</u>

- Trained professionals answer questions and address concerns.
- Support, assistance and resources are provided in English and Spanish.



# **Educational Information**

- A-Z Guide: <u>www.kidney.org/atoz</u>
  - Coping
  - Depression/Anxiety/Emotions
  - Living well
- Patient Stories:
  - Personal stories sharing experiences with depression throughout their journey with kidney disease and post-donation



# **NKF Online Communities**

- <u>https://www.kidney.org/online-communities</u>
  - Dialysis
  - Early Stage CKD
  - Living Kidney Donation
  - Transplant
  - Parents of Children with CKD

## **Questions?**



Kelli Collins, MSW kelli.collins@kidney.org 1.800.622.9010 x144

# **NKF Peers**

# nkfpeers@kidney.org

# 1-855-653-7337

www.kidney.org/patients/peers



# Use the "Question" box on your GoToWebinar panel to submit your questions

All unanswered questions will be reviewed by our co-chairs and speakers; they will be summarized in a Q & A document which will be posted to the Forum website after the webinar.





# Observations Challenges Successes

http://esrdnetworks.org/



Thank you for joining us! National Kidney Foundation<sup>®</sup> https://aakp.org/ https://www.kidney.org/

Visit the Forum website to download the Depression Toolkit:

http://esrdnetworks.org/resources/toolkits/patient-toolkits

Your local ESRD Network is also a resource:

http://esrdnetworks.org/membership/esrd-networks





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