An End Stage Renal Disease (ESRD) National Coordinating Center (NCC) Patient Education Webinar Event

January 5, 2021
• What is this call about?
• Today’s speakers
  ▪ Daniel Cukor, PhD
    - Director, Behavioral Health
    - The Rogosin Institute
  ▪ Glenda V. Roberts
    - Director, External Relations and Patient Engagement
    - Kidney Research Institute, University of Washington
• Topic: An Era of COVID-19: Surviving and Supporting Your Mental Health
• Questions and answers (Q&As) from chat and Q&A panels
What Is This Call About?

• Hear from experts who share tips for coping in a COVID-19 environment.
• Provide real-world experiences for others to put into use.
• Engage in bi-weekly calls on varying topics.
Online COVID-19 Resource

- Developed by patients for patients.
- Offers practical tips to help better deal with stress and anxiety.
  - Click on “For Patients.”
Daniel Cukor, PhD
Director, Behavioral Health
The Rogosin Institute
Coping With Pandemic Strain

Daniel Cukor, PhD
Director, Behavioral Health
The Rogosin Institute
January 5, 2021

Source: Pixabay
Where Are We?

1st Wave

Source: Pixabay
Patient Concerns

• Can I handle this again?
• Is it safe to travel? Is it safe to come into clinic?
• How are dialysis centers protecting patients?
• What if I have COVID-19? Will I die if I get COVID-19?
• Long term implications of COVID-19
• Is it safe to be around my family?
• Should I just stay home?
• Feeling of grief, loss, stress and depression
Burnout

• Characterized by emotional exhaustion or depletion.

  Signs of burnout:
  ▪ Feeling overwhelmed or worried
  ▪ Becoming easily irritated
  ▪ Feeling tired/changes in sleep
  ▪ Frequent headaches
  ▪ Turning to unhealthy coping (alcohol, drugs, food, etc.) more frequently
Allostatic Load

McEwen, 1999

Full Recovery

Time

Allostatic Response

Stress
Allostatic Load—Consecutive Stressors

![Graph showing Allostatic Load with consecutive stressors over time, leading to full recovery.](chart.png)
Complex Issues of 2020

Source: Pixabay
Profound Change to Life’s Domains

- Health challenges
- Changes to healthcare
- Home responsibilities
- Family responsibilities
- Older relatives
- Significant other—caregiving
- Community
- Withdrawal of usual means of support
Allostatic Load—Compounded Stress

![Graph showing Allostatic Response over Time with multiple peaks labeled "Stress" and a horizontal line labeled "Full Recovery".]
“Not till we are completely lost or turned around ... do we begin to find ourselves”
—Henry David Thoreau
Kintsugi

(Japanese) “to repair with gold”—the art of repairing pottery with gold lacquer and understanding that the piece is more beautiful for having been broken.
Resilience

Post-traumatic growth:
A positive psychological change experienced as a result of adversity and other challenges in order to rise to a higher level of functioning.
Allostatic Load—Adaptation to Stress

- Allostatic Load: Adaptation to Stress
- Full Recovery
- Time
- Allostatic Response
- Stress
Key Skills for Thriving and Surviving

• Managing worry
• Remaining socially connected
• Developing healthy life rhythms
Managing Worry

Source: Pixabay
What If …

• What if I need to go the hospital?
• Will my healthcare team be OK?
• Will I be infected?
• Will I get sick?
• Will I need to change shifts or sites?
• Will anyone I care about become ill?
• Is the vaccine safe? How can I get it?
Productive Versus Unproductive Worry

• Evaluate usefulness.
  ▪ If you can’t change it, no value in worrying about it.
Focus on the Now

• Present vs. future orientation
  ▪ Coping now
  ▪ Bringing resources with us
  ▪ What do I need to do for myself to be safe for the next 24 hours? Week? 3 months?

Source: Pixabay
Acceptance

It’s raining

• I don’t like rain.
• I wish it wasn’t raining.
• My day would be better if it wasn’t raining. My day is ruined. Everyday is like this.
• Why does it always rain the most when I want it to be sunny?
• It’s never going to stop.

Yup
Social Connection
Remaining Connected

• Challenge ourselves to create ways of remaining connected and infuse meaning in our lives in ways that are different.

• Thoughtfully choose how to spend time.
  ▪ Connect your actions to your priorities.
  ▪ Be productive.
  ▪ Use as bonus, free time.
  ▪ Get at your procrastination list.
  ▪ Accomplish something you would never have done.

“I just beat my 6 grandchildren in an online word game”—84-year-old.
Healthy Rhythms

Source: Pixabay
We Are Built for Routine

- Eat
- Sleep
- Exercise

Source: Pixabay
How Do We Build Resilience on a Personal Level?

1. Start with an honest assessment of what is going well and what is not.
2. Develop an “asset map”—who/what resources can you draw upon? *(Connect to others)*
3. Acknowledge your emotions. *(Manage your worry)*
4. Develop a plan for moving forward.
5. Make a plan for self-care. *(Healthy rhythms)*
7. Develop short-term attainable goals.
8. Celebrate your own successes, even if minor.
9. Accept that some things are challenging, now.
Online Resources

- ESRD National Coordinating Center

- National Academy of Medicine—Strategies to Support the Health and Well-Being of Clinicians During the COVID-19 Outbreak

- Center for Disease Control
  - https://emergency.cdc.gov/coping/selfcare.asp

- Emotional Wellbeing During the COVID-19 Outbreak
Adapting to the COVID-19 Pandemic: A Transplant Patient’s Journey

Glenda V. Roberts
Director, External Relations and Patient Engagement
Kidney Research Institute
University of Washington
Early Days: Before Things Got Real for Everyone

- February 6: Starting working from home
- February 29: 1st U.S.-reported death
  - First fatalities were dialysis patients.
  - They lived and shopped nearby.
- I was very, very worried.
  - Me: “Be wary of COVID-19!”
  - Them: “Very unlikely that any of you/us will get it.”
Initially, I Was Very, Very Afraid

- Self-isolated only with my husband.
- Stocked up on essentials.
  - Medication and food
  - Masks, gloves, and disinfectants
  - Water system and household essentials
- Everything is delivered.
  - Disinfected
  - Brought inside 24 hrs. later
Prepared My Family for the Long Haul

Avoiding Exposure

- Posted notices.
- Eliminated travel.
- Worked from home.
- Physically distanced from everyone.
  - Not 3, 6, 13, but 27 feet away
  - Except nephrologist & phlebotomist
  - Friends want to visit—“NO!”
  - Including my only child and his wife
COVID-19 Is Physically & Emotionally Stressful, Pt.1

“What Can I Control?”

- Maintain routines and rituals.
- Work and have a broader impact.
  - ASN COVID-19 Response Team
  - ASN COVID-19 Response Team, Transplant Subcommittee
  - eGFR and Race Taskforce (NKF & ASN)
  - Several webinar presentations
- Establish “work time” boundaries.
- Zoom family & holiday dinners.

ASN = American Society of Nephrology; eGFR = estimate glomerular filtration rate; NKF = National Kidney Foundation
“What Can I Control?”

• Make Zoom fun, instead of a burden.
  ▪ Hosted mocktail hours with friends.
  ▪ Hired personal trainer.
  ▪ Joined yoga class.

• Exercise—alone sometimes. 😊
  ▪ Weight training
  ▪ Walking
  ▪ Avoid the COVID-19.
COVID-19 Is Physically & Emotionally Stressful, Pt.3

“What Can I Control?”

- Focus on maintaining optimum health.
  - Practice COVID-19 good hygiene.
  - Eat kidney-friendly meals
  - Get enough sleep.
- Stay connected with friends.
- Read hardcover books.
- Respect our “me time.”
- Seek professional help, if needed.

Source: Pixabay
Let Us Hear From You

• Q&As from chat and Q&A panels
Online Patient and Family Member Resources

• View resources providing information about:
  ▪ What to expect as a newly diagnosed patient.
  ▪ Understanding the grievance process.
  ▪ Choosing transplantation.
  ▪ Choosing home dialysis.
  ▪ Infection prevention.
  ▪ Emergency planning.
  ▪ Caregiving.

• Get links to trustworthy organizations.

• Visit www.esrdncc.org/patient.
Where to Find Credible Information
About the Coronavirus 2019 (COVID-19)

During this pandemic, it’s especially important for everyone to take actions to keep themselves and others safe. To do this, let’s pause and think through how and where you can find credible, or trustworthy, information—especially as someone with kidney disease.

In stressful times, you may often turn to family and friends for support. Family and friends are great for:
- Verbal or receive emotional support.
- Connect with by phone call, video chat, or social media.

But your family and friends might not know the most up-to-date information on COVID-19 or the best actions to take right now, especially if you are on dialysis or have a kidney transplant. For this kind of information, you should turn to experts for credible information.

So, where can you find credible COVID-19 information? Start with these sites.

For general updates (e.g., handwashing and distancing, stay-at-home orders, use of masks) on COVID-19:
- CDC (Centers for Disease Control and Prevention)
- NIAID (National Institute of Allergy and Infectious Diseases)
- World Health Organization

For up-to-date kidney disease-related updates on COVID-19:
- On the Kidney Disease Improving Global Outcomes (KDIGO) website, you can learn about kidney-related COVID-19 health information and always to locate webinars from health experts and patient advocates.
- Go to the National Kidney Foundation (NKF), website for the most up-to-date resources on kidney disease from government, patient, and advocacy organizations.
- View the KDIGO Network for a directory of KDIGO Network Organizations, with information on kidney disease and dialysis help in your area.
- Check out the National Kidney Foundation (NKF) website for updates and resources on kidney disease and COVID-19 to see webinars, frequently asked questions, and health alerts about kidney disease and COVID-19.
- Look to Kidney Patients Canada (KPC), the kidney advocating organization, for read about how dialysis centers are working to keep patients safe and prevent COVID-19 from spreading.
- The National Kidney Disease and Transplantation Information Center (NKDTIC) provides information to help kidney patients manage their health during COVID-19, for ideas for kidney-friendly dating and coping strategies.
- Turn to the National Kidney Foundation (CKD) Network on COVID-19 tips on how kidney patients can stay physically and emotionally healthy.

TheKidneyHub.org is a safe, mobile-friendly web tool created by the ESRD NCC with help from kidney patients and family members.

Links to important new resources, such as:
- Quick Start to Submitting an Emergency Grant Request
- Understanding High Kidney Donor Profile Index (KDPI) and Increased Risk Kidneys video.
- And more.

Let us know what you think.
- Email us at NCCinfo@hsag.com.

Be a Friend, Share www.TheKidneyHub.org
Our Next COVID-19 Webinar Events

• Save the dates for our next events.
  ▪ Provider-focused event: January 13 at 3 p.m. ET
  ▪ Patient-focused event: January 19 at 4 p.m. ET

Visit [www.kidneyCOVIDinfocenter.com](http://www.kidneyCOVIDinfocenter.com) for information and to register.
Thank You!

NCCinfo@hsag.com
844.472.4250
813.865.3545
www.esrdncc.org

Additional COVID-19 resources for patients and providers:


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