



National Patient and Family Engagement- Learning and Action Network (NPFE-LAN) Kidney Caregiver Peer Connection Call

October 8, 2020

ESRD = End Stage Renal Disease



Before We Get Started

Please be respectful and remember:

- All lines are muted.
- The lines will be unmuted for questions.
- This call is being recorded and will be made public.
- Do not disclose any personally identifiable information.
- Do not ask for medical advice.
- Each person's situation and experience is unique.
- Before making changes to your health practices, speak with a member of your healthcare team.



Disclaimer

The views and opinions expressed during this call are those of the panelists and do not necessarily reflect the official policy or position of the End Stage Renal Disease (ESRD) National Coordinating Center (NCC) or the Centers for Medicare & Medicaid Services (CMS). Any content provided by the panelists is of their opinions and is not intended to substitute for professional medical advice, diagnosis, or treatment. Always seek the advice of your physician or other qualified health provider with any questions you may have regarding a medical condition.

The NPFE-LAN Team



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Panel of Caregiver Subject Matter Experts



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Tina Gee



Staying Connected During the COVID-19 Pandemic

- Telephone and text messages
 - The telephone is a great way to stay connected with others.
 - Agree upon a time to talk.
 - Decide who will call who. Use the text message for quick check-ins with each other.
- FaceTime™
 - Perfect for seeing and hearing people over the phone.
 - Works only on Apple™ products, so both individuals need an iPhone™, iPad™, iPod touch™, or Mac™ to use this service.

Tips for Connecting Remotely

Use this guide to learn how to use video calling during isolation and beyond



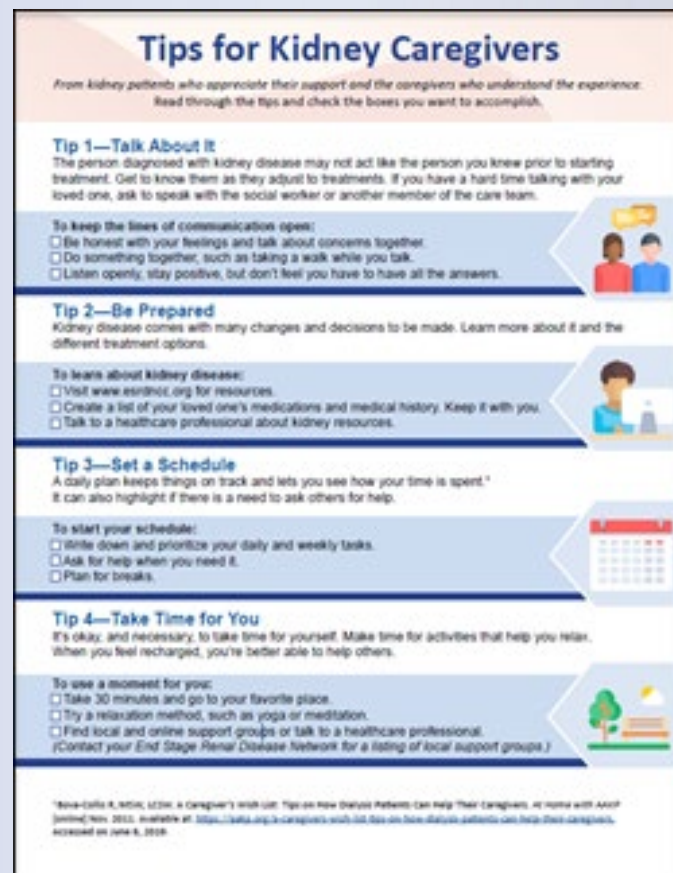
Staying Connected During the COVID-19 Pandemic (cont.)

- Google Hangouts
 - Available for both iOS™ and Android™ smartphones and mobile devices. Use for free voice and video calling and video conferencing.
 - Available for Windows™ and Mac™ desktop and laptop computers as well, so it synchronizes across all your devices.
 - Can use Hangouts for texting.
- Google Duo
 - Free video chat mobile app that enables one-to-one video and voice calls across both iOS™ and Android™ devices.
 - Available via Google's Chrome™ web browser on desktop and laptop computers.
- Messenger Apps
 - WhatsApp™; Facebook Messenger™
 - Used for instant messaging, sharing photos, videos, audio recordings and group chats.
 - Can be used to communicate on your phone but can also sync to your computer or tablet.
- Email

Caregiving Resources

For more information on caregiving visit:

- ESRD NCC: www.esrdncc.org/npfe-lan
- American Association of Retired Persons (AARP) Family Caregiving: www.aarp.org/caregiving
- Caregiver Action Network: www.caregiveraction.org
- ESRD Rockstars: www.esdrockstars.com
- Family Caregiver Alliance: www.caregiver.org
- National PACE Association: www.npaonline.org



Tips for Kidney Caregivers

From kidney patients who appreciate their support and the caregivers who understand the experience. Read through the tips and check the boxes you want to accomplish.

Tip 1—Talk About It
The person diagnosed with kidney disease may not act like the person you knew prior to starting treatment. Get to know them as they adjust to treatments. If you have a hard time talking with your loved one, ask to speak with the social worker or another member of the care team.

To keep the lines of communication open:

- Be honest with your feelings and talk about concerns together.
- Do something together, such as taking a walk while you talk.
- Listen openly; stay positive, but don't feel you have to have all the answers.

Tip 2—Be Prepared
Kidney disease comes with many changes and decisions to be made. Learn more about it and the different treatment options.

To learn about kidney disease:

- Visit www.esrdncc.org for resources.
- Create a list of your loved one's medications and medical history. Keep it with you.
- Talk to a healthcare professional about kidney resources.

Tip 3—Set a Schedule
A daily plan keeps things on track and lets you see how your time is spent.* It can also highlight if there is a need to ask others for help.

To start your schedule:

- Write down and prioritize your daily and weekly tasks.
- Ask for help when you need it.
- Plan for breaks.

Tip 4—Take Time for You
It's okay, and necessary, to take time for yourself. Make time for activities that help you relax. When you feel recharged, you're better able to help others.

To use a moment for you:

- Take 30 minutes and go to your favorite place.
- Try a relaxation method, such as yoga or meditation.
- Find local and online support groups or talk to a healthcare professional. (Contact your End Stage Renal Disease Network for a listing of local support groups.)

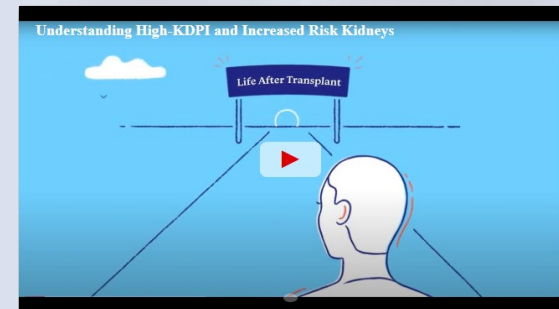
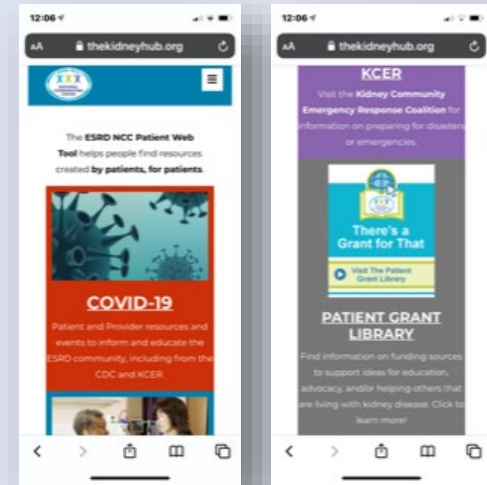
*Have a calendar, notebook, or use a caregiver's wish list. Tips on how dialysis patients can help their caregivers. At home with AARP (www.aarp.org). Available at: <http://www.aarp.org/caregivers-wish-list>. See on how dialysis patients can help their caregivers. Accessed on 04/18, 2019.

[Tips for Kidney Caregivers](#)

TheKidneyHub.org



- 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 Increase Risk Kidneys video.
 - And more.
- Let us know what you think.
 - Email us at NCCinfo@hsag.com.





Ways to Contact the ESRD NCC

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