

Looking Out for the Caregiver

This webinar will start shortly

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Looking Out for the Caregiver

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Results from DPC Survey in 2020

in collaboration with Kynetec



1 Responsibilities

Caregivers provide assistance with shopping (89%), housework (83%), preparing meals (77%), transportation (72%), and managing finances (69%).

More than **2 in 5** caregivers are providing **constant care**.

2 Hardships

Caregivers find the **emotional stress** of their duties as their most difficult hardship.

Most say they were **neither prepared** for the nursing tasks that the job encompasses **nor had a choice** in taking responsibility for their loved one.

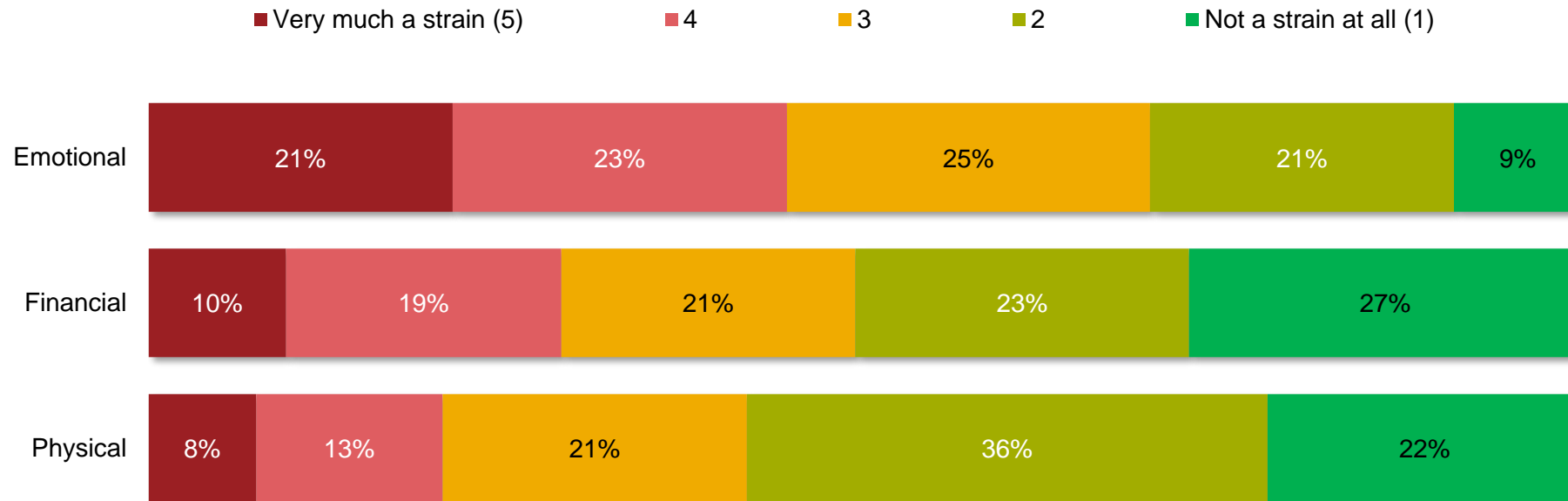
3 Information needs

Caregivers would like more information on how to **improve quality of life** for the CKD patient, information on how to **improve the quality of their own life**, and **resources** for caregivers.

About **1 in 5** are interested in participating in a live online support group.

Caregiver Stressors

The emotional stress of caregiving is very much a strain for more than 1 in 5 caregivers. Furthermore, more than 3 in 5 caregivers say they never had the choice in taking responsibility for their care recipient.



64%
of caregivers say they did not have a choice in taking responsibility for their care recipient

Base: Caregivers (n=146)

C14. How much of a physical strain would you say that caring for your [C4 CODE] is for you?

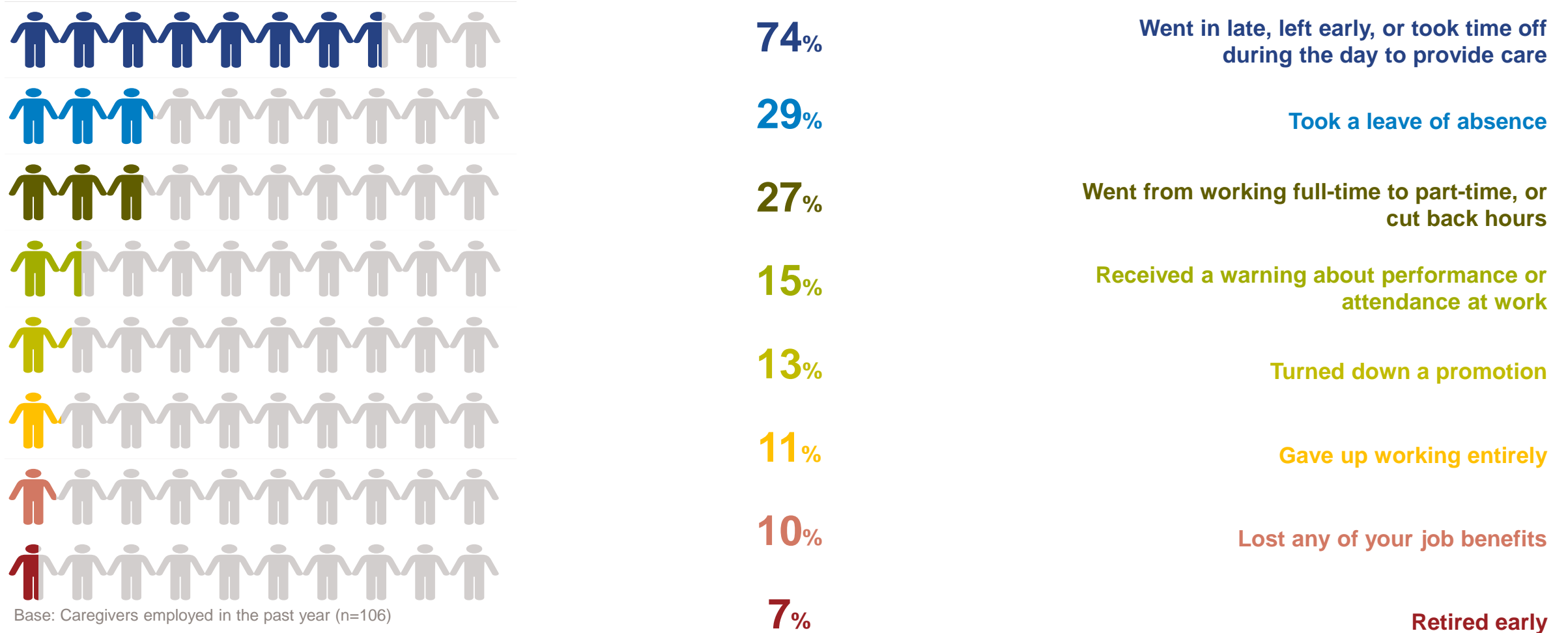
C15. How emotionally stressful would you say that caring for your [C4 CODE] is for you?

C16. How much of a financial strain would you say that caring for your [C4 CODE] is for you?

C17. Do you feel you had a choice in taking on this responsibility for caring for your [C4 CODE]?

Work-Related Struggles for Caregivers

Within the past year, nearly 7 in 10 caregivers juggled caregiving responsibilities and held a job *(not shown graphically)*.



Base: Caregivers employed in the past year (n=106)

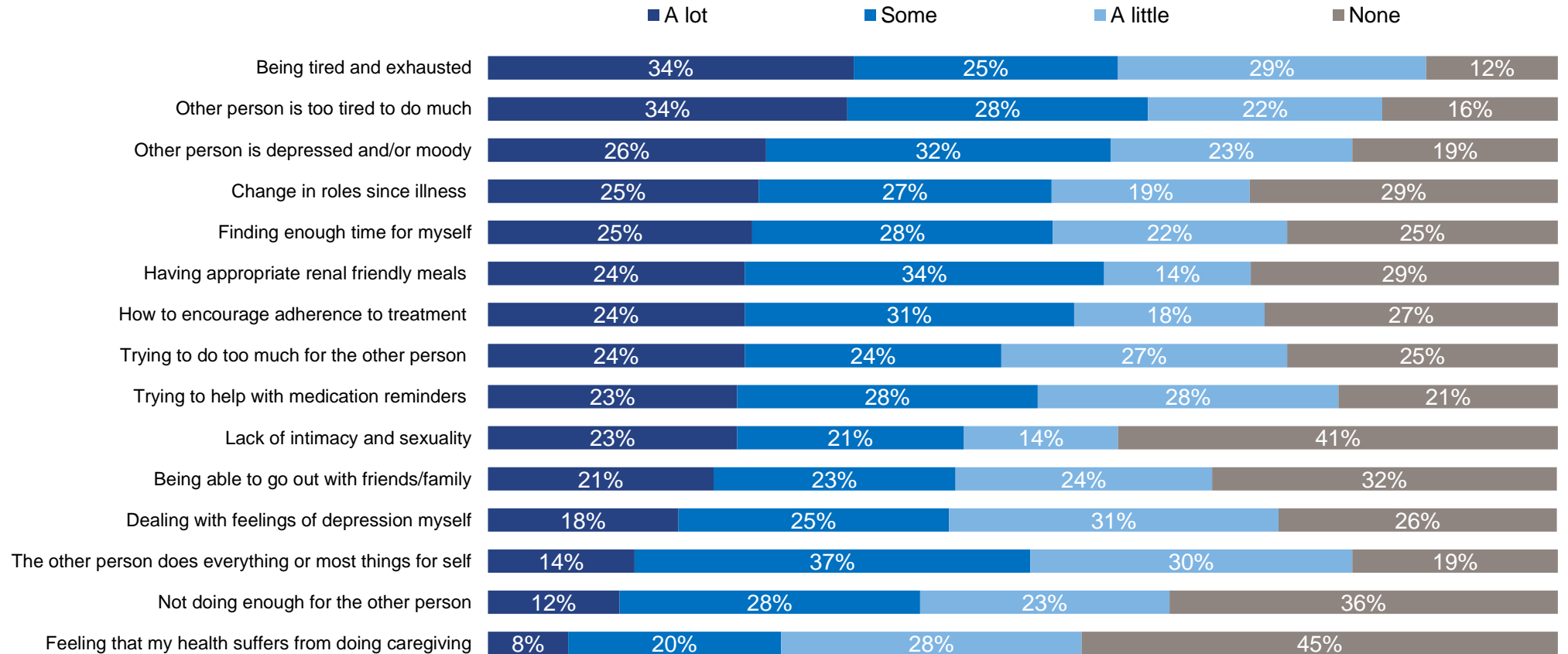
C18. Were you employed at any time in the last year while you were helping your [C4 CODE]?

C19. [ASK IF C18=1] As a result of caregiving, did you ever experience any of these things at work?

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Caregiver Challenges

The most frequent challenges that caregivers face are related to fatigue, whether it be themselves or that the care recipient is too tired/moody to receive and/or implement the help. Changing roles is also another challenge that is frequently mentioned.

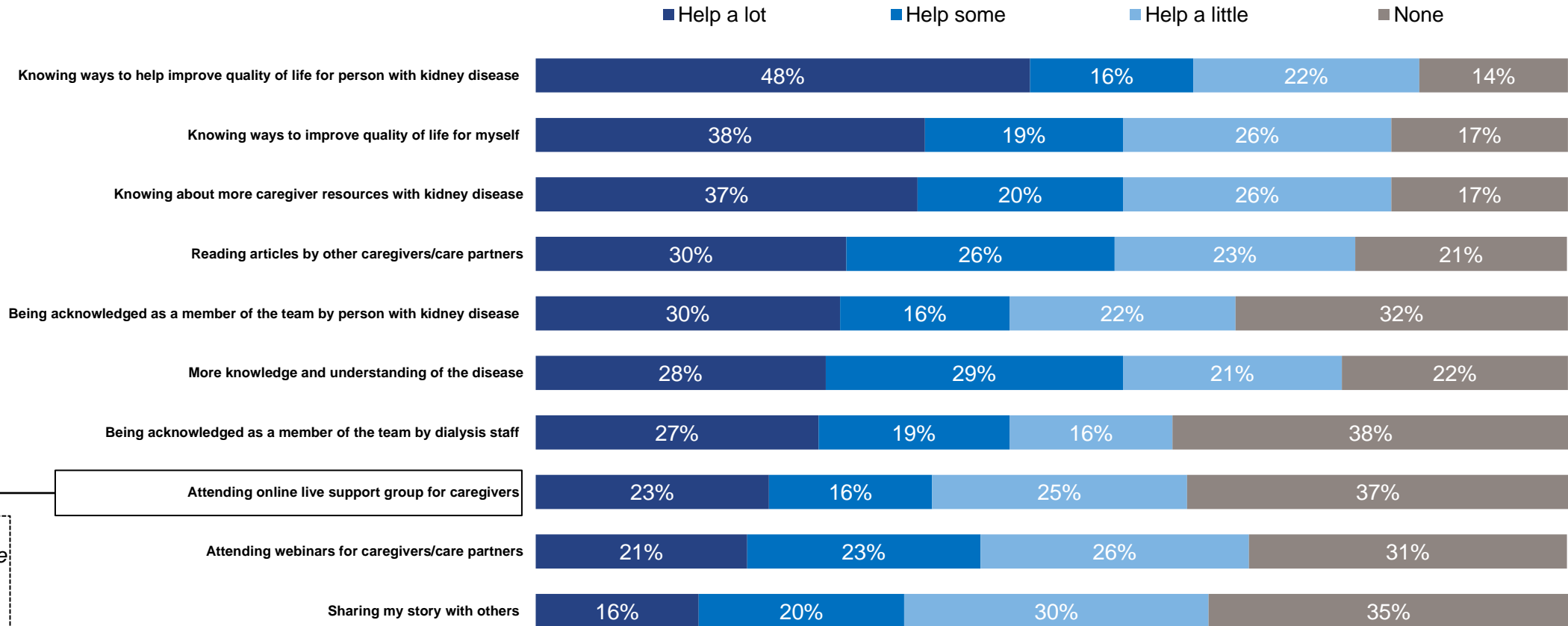


Base: Caregivers (n=146)

C23. What are your main challenges as a care partner? *Check all that apply and the level.*

Caregiver Needs

The most frequently mentioned caregiver need is centered around improving the quality of life for the care recipient.



**Only 20% of caregivers say they are interested in participating in an online support group*

Base: Caregivers (n=146)

C24. What would be most helpful to you as a care partner? *Check all that apply and the level.*

C25. Are you interested in participating in a live online support group with a professional, caregiver, and/or patient group leader(s)?

Summary of the data

- Caregivers are giving their best and are concerned for patient's quality of life (and their own).
- Mental and emotional health is impacted.
- How do I take care of myself while taking care of someone else?

Self-check

- What is going well for me?
- How am I feeling today? How has my mood been?
- What does my sleep look like compared to “normal”?
- What are my eating habits?
- What about relationships?- Am I keeping in touch with family and friends?
- How is my work going? Ability to focus on tasks?
- If I feel like things aren't going well, how do I handle it?
- Do I have ANY “me time” or self-care time?
- When is the last time I did something for fun?

General Habits

- Sleep hygiene- good bedtime routine, reduce screen time before bed, 8 hours of sleep
- Eating- healthy eating
- Exercise- traditional workouts OR stairs instead of elevator, parking further away
- Structure for my day/time
- Boundary setting!

Emotions

- How am I feeling?
- Am I trying to hide, ignore, or suppress emotions?
 - How's that going?
- Tips:
 - Allow yourself to feel.
 - Emotions are normal!
 - Be kind to yourself and give yourself grace.

Sadness

- Symptoms: sadness, withdrawal, apathy, irritability
- People can't support you if they don't know how you are really feeling.
- Tips:
 - Do something you **enjoy!** (MAKE yourself do this if it feels difficult).
 - **Social support** is key- communicate with others!
 - **Challenge negative thoughts** with reality

Sadness Exercise

Thought challenging

- What are some of your negative thoughts?
- What is some evidence for my thought?
- What is evidence against my thought?
- Alternate thought?

Anxiety or Worry

- Symptoms: stress, racing thoughts, tense, sweating, increased heart rate or breathing
- Worry does NOT go away if you avoid it and often it's counterproductive!
- Tips:
 - Set aside “worry time”- 15 minute window of time
 - Thought defusion

Worry Exercise

Thought acceptance and defusion

- Leaves on a stream
- Write down your worries on a piece of paper.

Relaxation

- Diaphragmatic breathing apps:
 - Calm, Headspace, Breathe2Relax
- Imagery
- Progressive muscle relaxation

Positivity

- Limit exposure to negative information/news stories/drama.
- Do an activity you enjoy.
- List one positive thing that happened during your day.
- List something you're thankful for or send a "thank you" email.

Self-Care

WHO: Self-care is what people do for themselves to establish and maintain health, and to prevent and deal with illness. It is a broad concept encompassing *hygiene* (general and personal), *nutrition* (type and quality of food), *lifestyle* (sporting activities, leisure, etc.), *environmental factors* (living conditions, social habits), *socio-economic factors* (income levels, cultural beliefs) and *self-medication*.

Self-Care

- Start small, pick ONE activity to focus on for the next week:
 - Social support- call or text a friend
 - Exercise- take the stairs instead of elevator
 - Healthy eating- eat a salad
 - “Me” time- take time to read

Goal Setting- SMART goals

Specific: What am I going to do or change?

Measurable: what is my frequency/distance/amount of behavior I am going to do?

Attainable: is the goal do-able (supplies, scheduling, support)

Relevant: how is this goal related to my overall health or good health?

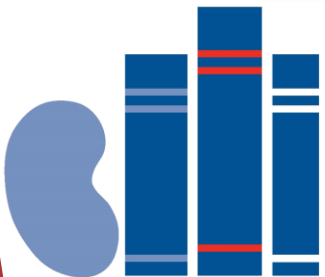
Timely: for how long will I enact this plan before I evaluate if it's working?

Summary

- Caregivers are dedicated...sometimes at the expense of their own emotional and physical health.
- Start doing regular self-checks to identify areas of concern.
- Engage in exercises for needed areas.
- Practice self-care and relaxation strategies.
- Seek social support.
- Seek out professional assistance when needed!

Questions?

Please use the Chat Box



*Thank
You!*



Additional Resources

Support groups:

- National Kidney Foundation (NKF): <https://www.kidney.org/online-communities>
- NKF resources: https://www.kidney.org/patients/resources_Caregiver
- AAKP (Amer Assoc. of Kidney Patients): <https://aakp.org/>

Additional Resources

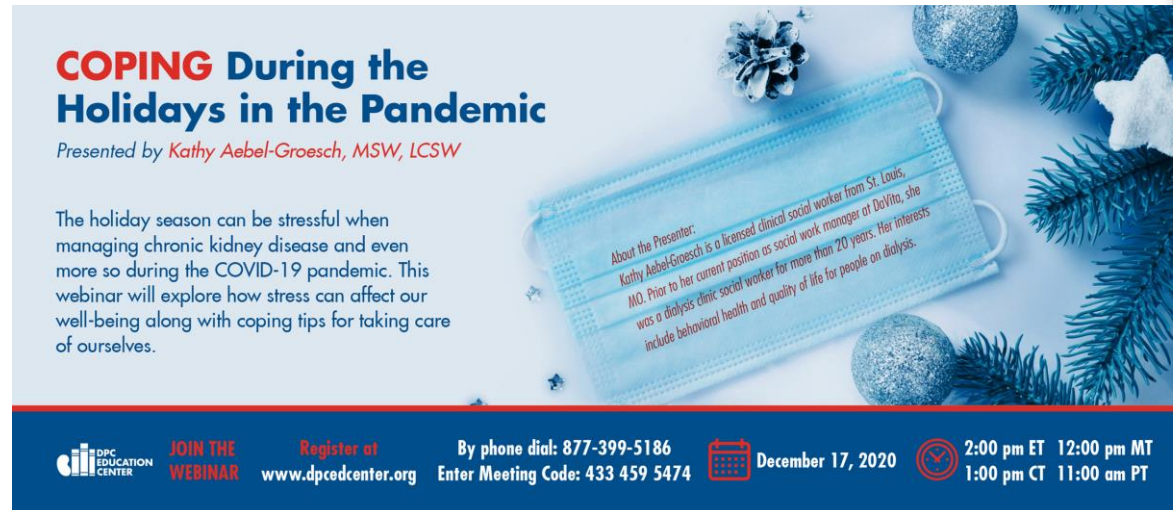
Support groups:

- Renal Support Network at www.rsnhope.org or 1-866-903-1728*
- Nationwide listing of support groups, by state*, at <https://aakp.org/support-groups/>
- DaVita* at www.davita.com/education/ckd-life/support/support-groups-for-people-living-with-kidney-disease or 1-800-244-0680

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Join us on for our next
webinar Dec 17th






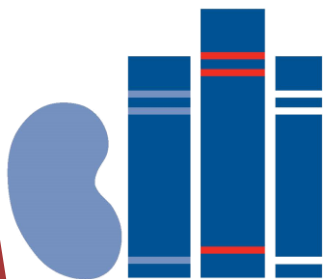
COPING During the
Holidays in the Pandemic

Presented by *Kathy Aebel-Groesch, MSW, LCSW*

The holiday season can be stressful when managing chronic kidney disease and even more so during the COVID-19 pandemic. This webinar will explore how stress can affect our well-being along with coping tips for taking care of ourselves.

*About the Presenter:
Kathy Aebel-Groesch is a licensed clinical social worker from St. Louis, MO. Prior to her current position as social work manager at DeVita, she was a dialysis clinic social worker for more than 20 years. Her interests include behavioral health and quality of life for people on dialysis.*

 **JOIN THE WEBINAR** Register at www.dpcedcenter.org By phone dial: 877-399-5186 Enter Meeting Code: 433 459 5474  December 17, 2020  2:00 pm ET 12:00 pm MT 1:00 pm CT 11:00 am PT



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