ESRD Patient News[©]

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We are right in the middle of summer heading towards the autumnal equinox. How has your summer been? What challenges did you face with the heat. There was record heat and flooding in many parts of the nation and now is a good time to look at your disaster plan.

Do you have the numbers of your dialysis clinic and social worker readily available?

Do you know where to go and how to get an alternate clinic if yours is closed down?

Do you have a current list of your medications? Are they all up-to-date with refills?

Do you have needed supplies on hand in case of issues with shipments?

We have available on our website <u>a number of resources</u> to help you be prepared for disasters. Please check those out and download them to ensure you have them on hand as needed.



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ESRD Patient News[®], a publication of The Carlisle-Williams Foundation, Inc, informs our readers of issues important to management and understanding of their disease and furthers the Foundation's mission of providing hope and support to ESRD patients. We welcome and encourage feedback. "Contact Us" on the website. Thank you!

Let's Make Everyday "Let it Go" Day

History of Let it Go Day

Thomas and Ruth Roy of Wellcat Holidays & Herbs are said to be the founders of the National Let It Go Day. They knew that many people live with the burden of regretful situations that quietly, yet constantly, weigh them down. The day was created to motivate people throughout the world to forgive themselves for happenings in the past and let go of their worries. It aims to highlight the ways to find positivity, contentment, and peace in life.

Regrets do little to no good; they weigh a person down; they can put a burden on the conscience and deprive you of the little joys of life. It is very important to learn to forgive yourself, to know when to stop blaming yourself for something, especially when there is nothing you can do to change what has already happened. The best thing to do in such a situation is to just let go of those feelings, and console yourself that there is nothing you can do about it. This will help you to move forward in life, grow, get rid of the bitterness and guilt, and allow you to make the most of life.

How to Observe Let it Go Day

Let go of your regrets

It is an occasion to let go of your baggage of regret. Let bygones be bygones, and start building yourself up for a happy, contented life.

Set intentions for a letting-go process

Make the decision that you will get rid of all the negative energy consuming you. Make a list of things to let go of, things you need to move on from, and start working on how to turn the tables over it.

Get some motivational or Let-it-Go decor

Add motivational quotes to your decor. Set your screen wallpaper to an inspirational quote to remind you of the positives in life. Create a happy playlist and enjoy yourself.

Five Things To Let Go Of

Regret

Usually, one can do nothing about the things in the past, so the best advice is to let that regret go (for your own sake).

Guilt

Other people might already have moved on, so why not you?

Grudges

It's not easy to let go of someone's poor conduct, but the best you can do for yourself is to hold no grudge and get rid of that negative feeling.

The past

For you to move forward in life, you have to let bygones be bygones.

Fears

Fears can stop us from exploring new things or doing what's important, so let go of them and move forward.

Benefits

It is a time to free yourself

It offers an opportunity to free yourself of negative energies and hard feelings that ruin your vibe or bring you down. Look forward to a happier, positive life, free from bitterness.

Mental peace is important

Mental health is as important as physical health. All the burden on conscience and negative energy takes a toll on our mental health, which should be cared for. On this day, people are reminded to pay attention to their mental health.

A day to relax

Rest is one of the most effective cures for mental illness. Why not just spend the day in a park or sit by the beach and enjoy the little happiness, joys, and satisfaction life brings in these small moments?

Solo Home Hemodialysis Can be Safe for Patients and Clinicians

Among the top three barriers to home dialysis, cited independently by both patients and clinicians, is the need for home-based support, according to data published in the *American Journal of Kidney Disease* in 2024.

The most recent USRDS Annual Data Report shows 14.5% of U.S. patients with end-stage kidney disease use home dialysis. For the 2.4% of patients who use home hemodialysis, the 2017 FDA clearance of the NxStage System One eliminated the requirement of assistance when using the machine at home during waking hours.

But whether clinicians knew it or not, patients were going solo before 2017, and others today are choosing unassisted HHD with systems not cleared for independent use, according to sources who spoke to Healio | Nephrology News & Issues.

Lisa Koester, a nurse practitioner at Washington University recently conducted a survey of her patients who used HHD. Half reported dialyzing unassisted and another 20% said they considered going solo, Koester said.

"Ask your patients how much their care partner is doing for them. You will find out there is a lot of solo going on," she said.

Joanna Lee Neumann, RN, CNN is senior director of clinical services quality at Satellite Healthcare in San Jose. In her opinion, risks for medical complications and mental health burden are too great to recommend solo HHD for all but a small group of patients.

"There are providers who are worried about solo," Osama El Shamy of George Washington University School of Medicine, said in an interview. "I need to make you as a provider more comfortable with solo, because otherwise you are depriving your patient of an option that you know they may be open to, and we have the technology to help support you as the provider to make you feel more comfortable."

Patient preferences

The discussion to allow unassisted HHD went public during a workshop that was part of the Kidney Health Initiative in August 2015, according to El Shamy.

"The FDA heard from patient representatives that argued that the care partner requirement really ruled out home treatment for a lot of patients," he said.

In 2017, a patient survey revealed 15% of HHD users routinely dialyzed independently, and of those who performed dialysis with a care partner, 16% reported going solo at least sometimes and 5% more than half the time.

"That was one of the first instances where the quiet part was said out loud," El Shamy said.

Fresenius Medical Care conducted the survey to support its application for FDA

clearance for the NxStage System One for independent use during waking hours. The company shared its unpublished survey data with Healio | Nephrology News & Issues.

Most respondents, including those who never went solo, said they were at least moderately confident in performing HHD tasks independently. Areas of least confidence were inserting needles and disconnecting — 41% and 39% of respondents, respectively, said they were slightly/not at all confident in performing the task by themselves.

When asked to consider all risks, including for needle dislodgement, hypotension and death, 60% of respondents said they would prefer solo HHD to in-center hemodialysis. Preference for solo HHD was stronger among younger, female, Black and employed patients.

'Not for everyone'

In the Fresenius Medical Care survey, 27% of the respondents using HHD with a care partner said they had physical limitations preventing independent HHD. Of those, 28% said they would choose in-center dialysis over solo HHD, if they did not have assistance at home. However, other respondents expressed psychological concerns, such as fear of inserting their own needles or uncertainties about machine setup or ability to handle problems on their own, as reasons to avoid solo HHD.

Patient empowerment is what matters, according to Rachael Buening, RN, BSN, lead nephrology clinical specialist at Dialyze Direct, a company that provides hemodialysis to patients in skilled nursing home facilities and at home.

"When we are able to customize patient care to each individual based on their current needs, it's a huge win for the patient," Buening told Healio | Nephrology News & Issues. "With all the technology we have access to, we can accommodate and empower patients to take charge of their health needs, giving them back the autonomy that most patients lose when going through health issues and advanced disease processes, such as end-stage kidney disease. We also understand [solo HHD] is not for everyone."

HHD has benefits over in-center hemodialysis. In the Fresenius Medical Care survey, patients cited "better physical and emotional health," "doing treatments on my own schedule," "shorter recovery time after treatment" and "working and/or participating in more activities" among other perceived benefits. Solo HHD can extend those benefits to patients without a care partner.

Performing HHD unassisted can have additional benefits, according to Buening. Patients can take control of their own health and without needing to rely on a care partner's schedule and ability. Patients' greater involvement can increase adherence to their treatment plan, treatment satisfaction and quality of life.

Benefits extend to care partners, too, who are at risk for burnout, according to Koester.

"[Solo HHD] allows the responsibility to fall on the patient as opposed to the care partner," she said. "Doing home dialysis gives them more control, and they learn reliance upon themselves, as opposed their care partners."

Making solo safer

Patients choosing solo HHD typically receive more training on how their dialysis machine works and how to calculate volume as well as on preventive care and identifying and responding to complications quickly, Buening said. Additional safety measures can include use of connected equipment, such as a Bluetooth blood pressure cuff that reports measurements and real-time communication with nurses through NxStage VersiHD with GuideMe software and Nx2me Connected Health. An alarm such as that from Red-sense Medical can detect needle dislodgment and bleeding. Buening also suggests an Alexa or handsfree cellphone for making emergency calls.

Patients dialyzing alone should prepare their space to have within reach all equipment and other desired items, such as a TV remote control or book, phone charger and flashlight, Koester said.

"People who do solo will tell you they have everything organized where the machine is, where their supplies are," she said. "And the nurse helps them figure this out."

Patients should also let someone know when they start and stop a dialysis session and leave a door unlocked in case emergency workers need access.

Patient-clinician agreement

For clinicians who do not want to pursue the official route, the waiver requirements might still provide reasonable guidance for talking with patients about solo HHD, he said. Points to cover include:

- sleep cycle assessment and agreement that the patient will dialyze unassisted only during waking hours;
- agreement that solo HHD will be performed in an appropriate chair and not a bed:
- home visits three times per year to assess safety;
- emergency plan review at every monthly visit;

- patients continue to meet selection criteria, such as stable cognitive functioning and comorbidities;
- treatment adherence; and
- informed consent.

Finally, the discussion should be noted in the patient's chart.

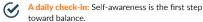
"This is really more about the patient than it is about me," El Shamy said. "Like in anything else, if I can't offer my patient what my patient is looking for, my patient is entitled to go and find someone who can."

Read the entire article here.



A Mental Health Toolkit

The 1-800-Flowers.com Connectivity Council suggests these 10 simple steps to boost your mental health.





Breathe deeply and intentionally: Just a few minutes of mindful breathing or quiet reflection can reset your perspective.

Make rest a priority: Changes in sleep patterns can signal emotional stress — listen to your body and honor your need for rest.

Move your body: Even a brief walk or stretch can boost your mood and energy levels.

Reach out and connect: A call, text, or coffee chat can provide real support for you and the person on the other end.

Practice gratitude: Write down a few things you're thankful for each day. It's a powerful way to shift your outlook.

Celebrate small wins: Progress isn't always big or loud. Every step forward deserves recognition.

Set healthy boundaries: Protect your time and energy, whether that means limiting screen time or carving out space to unwind.

Seek support when needed: Whether it's a friend, a counselor, or a professional therapist, asking for help is an act of courage and strength.