Network Coordinating Center Releases

Patient Experience Video Library

The End Stage Renal Disease (ESRD) Network Coordinating Center (NCC) recently announced the national release of its patient experience video library, available online at www.esrdncc.org (under the Patients tab, then Navigating the ESRD Journey). The videos include “Jay’s Story,” featuring an ESRD patient describing his challenges with obtaining information about his disease and highlighting the power of an online support community and informational resources to support both his experience of care and quality of life. Other videos include dialysis patients talking about their experiences, their concerns, and how they cope. The videos highlight patient empowerment, the importance of open communication with care team members, and patient safety in the dialysis facility. The videos encourage other patients to be informed, engaged, and to actively participate in their care. All of the stories are inspiring and empowering for patients, care partners, providers, care advocates, and healthcare stakeholders across the country. The NCC is now on Facebook and Twitter. You can LIKE them at www.facebook.com/esrd.ncc and follow them on Twitter (@ESRDNCC).

Let Your Voice Be Heard – Your Voice Matters!

Did you know that all of the Patient Services Program Activities for 2014 were based on the results of our Patient/Provider Educational Needs Assessments that were conducted in 2013? Now it’s your turn to provide direction for our 2015 programs by responding to our current Educational Needs Assessment which was developed with input from Network 13 Patient Subject Matter Experts. Two options for providing input: 1) Ask a staff member for a paper form for you to complete and return, or 2) Go to the applicable web address and complete it online. Home Patient: www.surveymonkey.com/s/PTHOME or In-Center Patient: www.surveymonkey.com/s/PTINCTR. Responses must be received by December 31, 2014 in order to be counted.

The Patient’s Voice—Meet a Network Volunteer

Amy H, Chair, Patient Advisory Council, Patient Subject Matter Expert (PSME) Network 13

Amy H is on a mission to educate others about healthcare. At a young age, Amy lost her mother to cancer. Remembering the support and care that had been provided during her mother’s illness, Amy decided on a career in healthcare. She has a Master’s in Business Administration with a concentration in Health Care Management from Our Lady of the Lake University and has devoted over 20 years to making a difference in her field. Amy’s commitment was strengthened with her own kidney failure and subsequent kidney transplant in March 1999. Amy has been very active in the “kidney community”. She was instrumental in starting a Peritoneal Dialysis support group at her center and served on the Executive Board and Patient Advisory Committee (PAC) of the ESRD Network 14 for ten years. She was also an active volunteer with the Southwest Transplant Alliance, promoting organ donation. Amy has worked with the Renal Support Network by traveling to Washington, D.C. to ask legislators to support laws concerning funding for research and medications for renal disease. She has spoken both locally and nationally on the importance of organ donation while providing a unique perspective as a patient and professional in the transplant community. Presently, Amy is a member of the Board of Directors & Chair of the PAC with Network 13 representing Louisiana, Arkansas & Oklahoma. She is presently employed with the Tulane Medical Center Transplant Institute in New Orleans as the Manager of Finance & Transplant Reimbursement. Through both her professional and volunteer work, Amy has clearly demonstrated that ESRD is a part of her life, but it does not define who she is.
In Control with In-center Self-Care, excerpted from Life Options Kidney School (www.lifeoptions.org)

Ok, just what is in-center self-care? Isn’t that what the nurses and technicians are for? Well yes, but knowing how dialysis works—how much water to remove, how to run the machine, putting in your own needles—can help you feel safer and more in charge of your life. During treatment, the facility staff teaches you how to do much of your own care, and they are on hand to help you. Self-care can be as simple as washing your fistula or graft site prior to treatment (infection control) or as complex as stringing your own dialysis machine, or self-cannulation (sticking yourself). Some of the other elements of self-care are: weighing yourself pre- and post-treatment, checking machine alarms to make sure they work, evaluating your access site daily, monitoring your treatment, holding your sites post treatment, exercising (there’s that pesky word again!), following your diet and fluid guidelines, taking your medication, and attending your care plan meetings as scheduled. People who actively participate in their care have: fewer hospital visits, more independence, higher self-esteem, and less fear of dialysis. You learn why and how things are done. You don’t have to do everything to take part in self-care. Even if you have poor vision or your hands don’t work so well, there are aspects of your care that you can learn about and do. The more active you are in learning about and managing your dialysis, the more in control you will feel over your life. **Volunteering as a patient subject matter expert (PSME) can give you the opportunity to develop Network educational programs which support self-care for yourself and other dialysis patients.** To learn more about self-care, ask your nephrologist, nurse, or social worker about your center’s options.

**Self-Care Quiz**

1. With in-center self-care, the staff is there to help.  
   **True**  **False**
   **True**  **False**
3. When learning how to do self-care, you may learn how to “stick” yourself.  
   **True**  **False**
4. You are the only person who can feel both the needles and your access.  
   **True**  **False**
5. You do not have to do everything to take part in your self-care.  
   **True**  **False**

When asked if he had ever participated in self-care while on in-center hemodialysis, here is what Thomas C., PSME had to say: “I took my blood pressure, listened/felt for my access and weighed myself before and after treatment and held my access after treatment. I felt better when I was helping not only the nurse, but more importantly myself; especially when there was a problem. A problem is not a problem, it’s an opportunity.”

**Thomas is an active volunteer for Network 13, serving on several patient-centered committees.**

**KIDNEY DICTIONARY**

**Involuntary Discharge:** A situation in which a patient is informed in writing that treatment at a dialysis facility will terminate in 30 days or the dialysis facility notifies the Network and State Agency that it is following an abbreviated termination procedure for a patient who has made an immediate severe threat of physical harm.

**Involuntary Transfer:** A situation is which a patient is dissatisfied with being transferred to another dialysis facility when the transferring facility temporarily or permanently ceases to operate, exist, or other circumstances.

Excerpted from Medicare ESRD Network Organizations Manual: Chapter 9 – Grievance and Patient Appropriate Access to Care. For more information about these terms see “Ask the Network.”

**Self-Care Quiz Answers:** 1. True; 2. True; 3. True; 4. True; 5. True
Learning and Action Network Campaign Update

Grievance Trend Quality Improvement Activity (QIA) “Increasing ‘On-Time’ Hemodialysis Treatment Initiation”

Ever feel like your treatments NEVER start on time? Well you are not alone. Network 13 completed a trend analysis on cases handled by their Patient Services Department. Cases from July through December 2013 were compared to cases from January through March of 2014. The Network analysis revealed that the “patient schedule/treatment start-end time” or “on-time performance” was the most common patient concern. On-time performance is defined as a treatment that starts 15 minutes before or after scheduled dialysis treatment time. What causes some of the delays that impact your treatment start time? Facility equipment and water issues are frequently cited for delays. You can’t receive treatment unless the machines are working and the water used for your treatments meets healthcare standards. The patient that sits in your chair prior to your treatment may have had bleeding or blood pressure problems, which needed to be stabilized before he or she could be discharged. A patient may have arrived late to treatment, causing delays in starting treatment on time. Have you ever been called in earlier than 15 minutes before your scheduled time? Well, that may impact the patient coming after you. Why? Patient schedules are staggered to allow specific take-off time for each patient. When your on-time changes, your off-time changes as well, and may overlap those of other patients in your section. Network 13 worked with six facilities in improving their on-time performance for this QIA. We assisted them in identifying the “root cause” for schedule delays. As a result of this activity, on-time performance improved by 17 percent in these facilities. The Network will re-evaluate the participating facilities in February of 2015 to ensure that improvements are maintained.

How are we doing?
The Network would like to have your input on how we are doing in meeting your Newsletter expectations. Please complete the short survey inserted in this newsletter and return it to your social worker, nurse, or technician who will in turn, forward it to us. Would you rather respond on-line?
Visit www.surveymonkey.com/s/3RCG3N6
Thank you for your help in serving you better!

Update from the Coalition for Supportive Care of Kidney Patients
The Coalition wants to remind everyone that ESRD patients who meet hospice requirements can receive dual benefits if the patient’s terminal condition is not related to ESRD. This means the patient can continue to receive dialysis and have the covered services paid under both the ESRD benefit and the hospice benefit.

We’re on the Web! www.network13.org

ATTENTION:
Network Grievance Process and Facilitation of Patient Access to Care
If you have a concern or grievance about the care you are receiving at your dialysis facility, the Network recommends that you first discuss your concern with your physician, nurse, or facility administrator. An open discussion with your caregivers may resolve your problem. If your concern is not resolved, contact the Network for assistance at 1-800-472-8664. You can always contact the Network prior to discussing your concerns with the facility staff, and if you are uncomfortable giving your name, you can report a concern to the Network anonymously. The Network also works to ensure patients have access to outpatient dialysis treatment and can assist facilities and patients to avoid involuntary discharge. If you have difficulty finding placement in an outpatient dialysis facility or have been told you are at-risk for involuntary discharge from your current facility, call the Network to discuss your case.
I just read the definitions for Involuntary Discharge and Involuntary Transfer in the Kidney Dictionary; can dialysis centers really do that? What would happen to cause that?

The short answer is yes, they can. Patients may be discharged from a facility under the following conditions:

1) The facility **ceases to operate**. A natural, weather-related disaster caused the facility to close its doors because it was destroyed and could not be rebuilt or repaired in a timely manner resulting in an **involuntary transfer**.

2) The patient’s **attending physician discharges the patient** from his or her care. When the attending physician notifies the patient, he or she also notifies the treating facility. The facility will in turn issue a 30-day discharge notice to the patient, the Network, and the state agency. If the patient is unable to find a physician who will accept him or her, the patient will be involuntarily discharged. The facility cannot treat patients who do not have a doctor to oversee their care.

3) The patient makes a threat to hurt another patient or staff person. This considered an **immediate severe threat**. Any threat is taken seriously. If this happens a patient may be discharged without a 30-day notice.

4) A patient commits **ongoing abusive and/or disruptive behavior**. For instance, the patient curses at or calls other patients and/or staff names, has been asked not to, but does so anyway. This continues even after the facility has counseled the patient several times and attempts to change the patient’s actions have been unsuccessful. When this occurs, the patient is given a 30-day discharge notice.

5) **Failure to place**. This occurs when attempts to find another doctor or clinic to treat the patient have failed. The patient must then seek treatment in a hospital emergency room. This increases the patient’s risk of worsening medical conditions and death.

Though the Network works with facilities to avert involuntary discharges, we cannot force them to keep patients. It’s a good idea to remember and practice the “golden rule” to prevent conflict from arising. Check out our flyer, **Tips for Good Communication with Your Healthcare Team** at [www.network13.org/PDFs/NW13_QoL_CommsTips_FINAL_508.pdf](http://www.network13.org/PDFs/NW13_QoL_CommsTips_FINAL_508.pdf).

## RECIPE

### Holiday Morning French Toast

**Portions:** 9 3x4” piece servings

**Analysis:**
- **Calories:** 428
- **Protein:** 19 g
- **Carbohydrates:** 60 g
- **Fat:** 16 g
- **Cholesterol:** 170 mg
- **Calcium:** 81 mg
- **Fiber:** 2.8 g
- **Potassium:** 200 mg
- **Phosphorus:** 132 mg
- **Sodium:** 363 mg

**Ingredients:**
- 3/4 cup brown sugar
- 1/2 cup unsalted butter, melted
- 3 teaspoons cinnamon, divided use
- 3 large tart apples, peeled, cored, and thinly sliced
- 4 oz. dried cranberries
- 1 loaf Italian bread, cut into 3/4” slices
- 6 large eggs
- 1-1/2 cups rice milk, unenriched
- 1 tablespoon vanilla

**Directions:** Peel, core and thinly slice or chop apples. In a 9” x 13” baking dish, combine brown sugar, melted butter and one teaspoon of cinnamon. Add apples and cranberries; toss well to coat. Spread apple and cranberry mixture evenly over bottom of the baking dish. Cut bread into 3/4” slices and arrange on top of apples. Mix eggs, rice milk, vanilla and remaining 2 teaspoons cinnamon until well blended. Pour mixture over bread, soaking bread completely. Cover and refrigerate 4 to 24 hours. Preheat oven to 375° F. Bake covered with foil for 30 minutes. Uncover dish and bake 15 minutes or until top starts to brown. Remove dish from oven and let stand for 5 minutes before cutting into 9 servings. Serve warm. Optional: Dust top with powdered sugar before serving.