

Heartland Headlines

A Special Publication
for people with kidney disease.

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- ...and more stories just for you!

Patient to Patient

For more information, to request a printed copy of this newsletter or to file a grievance, please contact:



Qsource ESRD Network 12
920 Main, Ste. 801
Kansas City, MO 64105

Phone: **800-444-9965**

E-mail: net12@nw12.esrd.net

Web: www.heartlandkidney.org

Resource: www.mykidneykit.org

Social Media:

www.facebook.com/heartlandkidney

Your feedback is important to us!
Visit <http://bit.ly/2DjNTas> to tell us
what you think of this newsletter.

Throughout this issue, you will see a
magnifying glass symbol.



When you see that symbol, you can
find more information in the MY
KIDNEY KIT (at the dialysis clinic)
or online at www.mykidneykit.org.

NOTE: All individuals featured in this
publication have given consent to release
their name, image and information in
regards to discussed content.

This resource was developed while under contract with the
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Heartland Kidney Network is now Qsource ESRD Network 12

Heartland Kidney Network is transitioning to a new identity.

While we will still provide the same support, educational opportunities
and resources as we have in the past, we will be now be known as
Qsource ESRD Network 12, reflective of our parent company's identity
and inclusion of ESRD capabilities.

The name transition aligns with a national trend to have End Stage
Renal Disease (ESRD) Networks identify by their Network number
rather than a specific name that depicts location or service area. We
will continue to serve the ESRD patients and clinicians in Nebraska,
Kansas, Missouri and Iowa.

We're still the same Network – only now you have access to a
broader array of services and educational opportunities through
our collaboration with other ESRD Networks, Quality Improvement
Organizations and national partners.

A graphic featuring two women, one in a green shirt and one in a pink top, looking at a laptop. In the background, there is a map of the Heartland region (Nebraska, Kansas, Missouri, Iowa) and a magnifying glass icon. The text 'Contact Us' and 'We're Here for You!' are also present.

Contact Us
for information about living
well with kidney disease
or if you have a concern
about your care.

We provide free information,
assistance and confidential
mediation to the ESRD
community.

We're Here for You!

Patient Toll-Free Line
1-800-444-9965

For more information or to file a grievance, please contact:
Qsource ESRD Network 12 | 920 Main St., Ste. 801 | Kansas City, MO 64105 | net12@nw12.esrd.net



Ticket to Work Program Supports Career Development

Are you between the ages of 18 and 64 years old and interested in working? Social Security’s Ticket to Work program supports career development for people who get Social Security disability benefits.

The Ticket to Work program is free and voluntary and can help YOU progress toward financial independence. Ticket to Work connects you with free employment services to help you decide if working is right for you, prepare for work, find a job or maintain success while you are working.

While participating in the program, you will receive services such as career counseling, vocational rehabilitation, job placement and training from authorized Ticket to Work service providers such as Employment Networks or your state Vocational Rehabilitation agency.

For more information call the Ticket to Work Help Line at **1-866-968-7842** or visit <https://www.choosework.ssa.gov>.



To find the Vocational Rehabilitation office near you contact one of the offices below. We’ve provided shortlinks for easy access to their websites.

Iowa | Vocational Rehabilitation Services
800-532-1486 or <https://bit.ly/2Xku6Ay>

Kansas | Rehabilitation Services (SRS)
866-213-9079 or <https://bit.ly/2GmfLn>

Missouri | Vocational Rehabilitation
877-222-8963 or <https://bit.ly/2lp2xT5>

Nebraska | Vocational Rehabilitation Services
877-637-3422 or <https://bit.ly/2Zi6C0o>

Honoring a Life Well Lived

Remembering Ardy Boucher | 1949-2019

On behalf of Qsource ESRD Network 12, the staff, Board of Directors (BOD), Medical Review Board (MRB) and Patient Advisory Council (PAC) it is with great sadness and gratefulness that we honor the life of Ardyth (Ardy) Boucher in this issue of *Heartland Headlines*.

Ardy's incredibly positive outlook, determination and advocacy on behalf of people living with kidney disease was truly inspiring.

Ardy served the kidney community in many ways throughout her years on dialysis and a kidney transplant recipient.

As far back as 1996, she shared her time and talents on the Board of Directors, Medical Review Board and Patient Advisory Council. She served as PAC Chair from 2009 through 2014.

Ardy was a wife, mother, grandma, and great grandma. She worked in dialysis for 27 years. There she often shared her story with other patients and encouraged them to live well with kidney disease. She was also an active member of her church and volunteered with the National Kidney Foundation.

Ardy was diagnosed with kidney disease at 14 and began dialysis at 22. She had two kidney transplants — the first in 1973 and a second in 1983 that she received from her brother which lasted 27 years.



She decided to do home hemodialysis with the support of her husband and care partner, Jimmy. Ardy could always be counted on to provide her insight and helped by sharing her story and giving feedback on the educational resources the Network develops to support patients.

She passionately encouraged other patients to be engaged and informed about their healthcare and shared her positive outlook to inspire others to live well with kidney disease.

We will continue to share her message to people living with kidney disease.

In Ardy's own words: "You can live a full and productive life on dialysis by keeping a positive attitude, keeping relationships with friends, keeping faith and remembering that life is a gift and we should embrace it, love it, and live it to fullest."

Thank you Ardy, for sharing your life with us.

Patient to Patient

Finding Strength on the Journey through Advocacy

My name is Rowena Laura Novy and I am a 41 year old, single mother of two boys.

My kidney journey began 23 years ago, when I was 18 years old. Protein was found in my urine and I was referred to a nephrologist.

I went to my doctor's appointment without my parents and I didn't get enough information about what was really going on with my kidneys. I didn't take my medicine as prescribed or get my diet in order. I don't think that I was educated well enough about my disease.

In 2006, I was diagnosed with Lupus and then found out I was pregnant. The pregnancy with my second son in 2007 was high risk and I had to deliver early because of the stress on my kidneys. During an emergency check-up four weeks later I was sent to the hospital for a blood transfusion and to have a peritoneal dialysis (PD) catheter placed.

The doctor said that the stress of the pregnancy on my kidneys caused them to fail. I didn't know the symptoms of kidney disease, I just knew that I wasn't ok because all I was doing was sleeping and waking up to breastfeed. Training was done quickly and I didn't even have a choice of the type of dialysis I would do. The doctors just figured as a new mother and college student PD would be best for me because it would give me more freedom throughout the day.

I started on PD and was on it for seven years before I was blessed with a kidney transplant in December 2014. The kidney lasted about 18 months and failed because I was diagnosed with H1N1 and pneumonia and was hospitalized for eight days.



**My Network:
NPR and PAC**

Rowena "Laura" Novy

Patient Advisory
Council (PAC) Member
Network Patient
Representative at Davita-Omaha South

Subject Matter Expert for the National Patient and Family
Engagement Learning and Action Network



The kidney failure was a slow process and doctors tried everything to try to save my kidney, including plasmapheresis and IVIG treatments. I've been on in-center hemodialysis since 2016.

I've had to overcome a lot throughout my kidney journey. I don't have a lot of family in town, only my kids, my sister-in-law and a handful of friends. I get my support from them and going to church and praying.

When times get hard I have my kids to keep me going. I want to live to see my sons graduate, to have children, and to become husbands and productive members of society.

Keeping a positive attitude is half of the battle.

Being an advocate for myself and educating other dialysis patients as I educate myself helps to motivate me. I've finally realized that it's not the doctor's responsibility to know everything about me when they have many other patients. **It's my body and I should care about it most!**

I started following doctor's orders and taking care of myself better, I'm currently in the process of getting relisted for another kidney transplant.

Whatcha Packing?

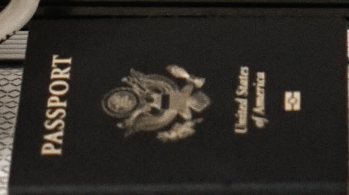
Travel Checklist for People on Dialysis

Many dialysis patients often say to themselves: “I can’t travel. I’m on dialysis.”

Oh...but you can!

It just takes some planning.

Here are some steps to get you started on planning your next vacation.



Checklist For Travel

- ☐ Talk to your doctor, nurse and social worker to let them know about your travel plans. They will be able to give you important information for your trip.
- ☐ If you have private insurance be sure to call your insurance carrier to find out what expenses are covered.
- ☐ Locate a dialysis clinic where you are staying at least two months in advance of your visit.

Talk to your social worker or you can visit Dialysis Facility Compare at: <http://www.medicare.gov/dialysisfacilitycompare/>.

Whether you dialyze in-center, at home or with peritoneal dialysis, you should locate a dialysis clinic in the city you are visiting.

It is very important to know where to go in case you need help or forget something.

- ☐ Carry the name, address and phone number of the dialysis clinic in the city you are visiting with you during your trip.
- ☐ Pack your medical information in your carry-on luggage and bring it with you to dialysis.
- ☐ Bring along extra medication in case you get delayed while traveling.

Travel Planning Tips for Home Patients

- ☐ Tell your care team if you are going to be gone for more than 1-2 days or if you are flying.
- ☐ Contact your clinic nurse so they can help coordinate with the back-up clinic. Patients on peritoneal dialysis and home hemodialysis should have a back-up clinic.
- ☐ Contact your dialysis supply company 4-8 weeks before your trip. They may be able to ship your supplies to where you will be staying if you are going to be away for a long time.

Home dialysis machines that are 100 pounds or less with the case can be carried onto airplanes. The machine is an “assistive device” and the airline must let you bring the machine on the plane or check it. The machine does not count toward a carry-on bag limit and they cannot charge a checked baggage fee.

For more information visit: www.transportation.gov to see the guidance on traveling with the dialysis machine.

Portable Dialysis Machine Notice for Travelers with Disabilities: <https://bit.ly/2uVb33I>

Be Prepared When You Fly with a Dialysis Machine: <https://bit.ly/2D6QTYN>

For more information check out the MY KIDNEY KIT page
MY LIFE: Traveling with Dialysis.



Patient Peer Insights

We asked several patients to share their thoughts on a few topics: Vocational Rehabilitation, Transplant, Home Dialysis and Infection Prevention. Read on to get an insight to their stories.



Laura
Novy



Kim
Lyles



Yvonne
Steele



Sean
Noble



Jerry
Ribbing



Mike
Bronson



Mike
Warner



Chris
Eichmeier

Several of these patients will also be on our special VIP Peer to Peer Sharing Call series which begins April 24th. We invite all patients and their family members to call, listen and ask because you are all Very Important Patients.

Very Important Patient: Peer-to-Peer Sharing Calls

The Heartland Kidney Network Patient Advisory Council (PAC) would like to invite people living with kidney disease to a special call in series. We welcome patients, family members and care partners to call in to listen and ask questions of members of the PAC about their experiences with the call topics. It's your opportunity to get information and advice from patient peers.

Call-in # 888-537-7715 | Access Code: 885 90 323#

Wednesday, April 24 | 1-2 p.m. CT



Wednesday, May 29 | 1-2 p.m. CT



Wednesday, June 26 | 1-2 p.m. CT



Wednesday, Sept. 25 | 1-2 p.m. CT



Focus On Vocational Rehabilitation

Vocational rehabilitation (VR) is a state program that helps people to return to work, go to school, or find another job. VR services can help remove some of the barriers that patients often deal with when trying to balance work and getting dialysis. The benefits of working are not just about money, but can help your quality of life by giving you something to look forward to, giving you more freedom, helping you to meet new people and improving your self-esteem.

Why do you want to return to work?

Laura Novy: I am a divorced, single mother of 2 boys and I need to provide for my children. Seeing my children step up and be amazing caregivers aided my desire to begin my search and return back to work. In Nebraska, I worked with a program through Social Security that helped me with my resume. | Laura Novy is on in-center hemodialysis.

Kim Lyles: The support of my family and friends, as well as Vocational Rehabilitation services, aided my decision to return to work. Returning to work would take a lot off of my mind and hopefully help me find a normal routine in life. Vocational Rehabilitation services gave me an idea of what my interests were pertaining to work. | Kim Lyles received a kidney transplant in January 2019.

Yvonne Steele: I wanted to return to work to provide for myself financially. Dialysis changed my life which resulted in me having to sacrifice and make changes; especially in my career as a cosmetologist. This process has not been easy but having a good mentality through it all is important and by doing Peritoneal Dialysis (PD), I was able to return to work part-time. | Yvonne Steele is on continuous cycling peritoneal dialysis.

Call in and join us for the VIP: Peers talk about Vocational Rehabilitation on May 29, 2019 from 1-2 pm CT or listen to the recording afterwards online at <https://bit.ly/2GpnUjI>.

Join the call to hear patients living with kidney disease talk about their experience with vocational rehabilitation services. Call, Listen, Ask and Learn from other patients to help you live your best life with kidney disease.



**My Life:
Occupation**

Focus on Transplant



My Choices

Who and what motivated you to seek a kidney transplant as a treatment choice?

Sean Noble: I wanted my freedom back. I wanted a normal life badly. In a sense, I felt “bound to dialysis”. Thankfully, I had the financial backings and insurance to aid the procedure. I knew that with a transplant, I would have been able to travel and attend my children’s events-essentially; I would have more family time. | Sean Noble received a kidney transplant in November 2013.

Jerry Ribbing: My family was my main motivation. My wife worked in the medical field and wanted to see me have a better quality of life. At first, I was not eligible for a transplant because of my health but now I am. I am blessed that my wife as well as two family friends volunteered to give me a kidney. | Jerry Ribbing was recently listed for transplant.

Mike Warner: A kidney transplant was the best choice for me. It is so much better than dialysis. I wanted to be free from a life of dialysis. Informative conversations with my doctor and my intensive own research motivated me to get a kidney transplant. | Mike Warner received a kidney transplant in January 2017.

What advice would you like to share with other patients about transplant?

Mike Bronson: I chose transplant because it was the closest to my “normal” life. Stay in good condition. Make sure you do what your doctors tell you to do, you show up on time for your appointments, follow your diet and get exercise. Exercise will help you to be prepared for the surgery and helps with recovery after the surgery. Ask questions if you do not understand something. | Mike Bronson received a kidney transplant from a living donor in October 2009.

Jerry Ribbing: Get educated and use the resources that are available. I got involved as a Network Patient Representative and now am on the Patient Advisory Council with the Network. The Heartland Kidney Network has helped to clear up many misconceptions about transplant and provided me with a lot of factual information. Depression is a big obstacle during this process. Don’t go there. Optimism and faith have helped me.

Mike Warner: I would highly recommend a kidney transplant; it was the best solution for me. Stay patient and go with the flow. Live in the moment. When you have trouble, let it roll off... don’t stress. Get involved in helping others as a Network Patient Representative and look for information, don’t be afraid to ask your doctors and educate yourself.

Listen to the April 24, 2019 VIP: Peers talk about Transplant online at <https://bit.ly/2GpnUjl>.

Hear patients living with kidney disease talk about their experience with kidney transplant. Call, Listen, Ask and Learn from other patients to help you live your best life with kidney disease

Focus on Home Dialysis

What advice do you have for someone thinking of moving from in-center dialysis to home dialysis?

Mike Warner: You'll become freer than you would in-center! I'd recommend peritoneal dialysis (PD) to everyone. It is so important to be educated on doing dialysis at home. I've had a few complications because PD is not a perfect treatment but it is better than in-center. I wasn't extremely tired and restless after every session like I was in-center. | Mike Warner was on PD for several years before getting a transplant.

Yvonne Steele: PD dialysis was the best decision I've ever made. I automatically loved PD. I was educated for two years before needing to start dialysis and deciding to pursue PD. I have now done PD for ten years. There are no schedules, only freedom! I would suggest sharing your experiences with others on dialysis; be inspirational and lift people up. You can live a normal life on dialysis! | Yvonne Steele has used a cyclor to do her PD for the last 10 years.

Laura Novy: I would recommend trying home first. I had freedom instantly with PD, I had more free time. I was more able to attend my kids school events and spend time with family more. My advice would be to advocate for yourself and get educated. | Laura Novy was on PD for seven years and is on in-center hemodialysis currently.

How did you prepare to travel while being on home dialysis?

Yvonne Steele: Dialysis doesn't stop me from traveling. I can bring my cyclor where ever I go. I make sure to give my clinic a few weeks' notice so I'm prepared. I make sure to use my cyclor every night just like at home.

Laura Novy: I did fly while on dialysis. Let the clinic know beforehand so supplies can get sent. TSA thoroughly checked me and I almost missed my flight, make sure you plan for plenty of time to go through security.

Sean Noble: I was able to bring all my treatment supplies on the airplane. I didn't have any problems and did my dialysis each evening. | Sean Noble was on home hemodialysis before receiving a kidney transplant.

Call in and join us for the VIP: Peers talk about Home Dialysis on June 26, 2019 from 1-2 pm CT or or listen to the recording afterwards online at <https://bit.ly/2GpnUjl>.

Join the call to hear patients living with kidney disease talk about their experience with peritoneal dialysis and home hemodialysis. Call, Listen, Ask and Learn from other patients to help you live your best life with kidney disease.



My Choices

Focus on Preventing Infections

What do you do (beyond the dialysis center) to take care of your access (fistula or graft) to stay infection free?

Jerry Ribbing: I keep my access clean and inspect it for any problems several times a day. I am super thorough with cleansing methods and keeping germs away from it. | Jerry Ribbing is on in-center hemodialysis.

Chris Eichmeyer: I make sure my access is clean. I bathe with a wash cloth and soap and haven't had any difficulties by making sure it's cleaned properly. I also use disinfecting pads. | Chris Eichmeyer is on in-center hemodialysis.

What do you think patients need to know to help them stay infection free?

Mike Bronson: Wash your hands thoroughly and always wear a mask when needed or required. Make sure those who are caring for you during your sessions are keeping their hands clean and wearing a mask. Stay on top of all infection prevention rules. Put your health first. | Mike Bronson received a kidney transplant in October 2009.

Jerry Ribbing: Patients need to understand that their health is at risk if they don't thoroughly take care of their access. Taking responsibility for your health is extremely important. Cleanliness is next to Godliness and it applies to infection prevention.

Chris Eichmeier: Technicians should explain what they are doing, so that patients can understand the process and know if things will be done properly. Don't be afraid of asking questions.

Do you feel comfortable speaking up about any concerns so that staff are reminded to follow the best infection prevention practices?

Chris Eichmeier: Yes, I have filled out many reports grading the nurses and patient care technicians on their infection prevention practices, like hand washing, wearing gloves and masks.

Jerry Ribbing: Absolutely! A technician had to remove the needle from my arm and I reminded her to put gloves on before doing so. I noticed she had not been following safety precautions. She had been helping other patients before me and had not washed her hands or put on new gloves.

Call in and join us for the VIP: Peers talk about Infection Prevention on Sept. 25, 2019 from 1-2 pm CT or listen to the recording afterwards online at <https://bit.ly/2GpnUjl>.

Join the call to hear patients living with kidney disease talk about how they stay infection free. Call, Listen, Ask and Learn from other patients to help you live your best life with kidney disease.



**My Treatment:
How Can I Stay Infection Free**

Treat Your Feet!

It is important to take care of your feet — especially if you have diabetes. According to the Centers for Disease Control and Prevention, between 60 to 70 percent of people with diabetes have diabetic neuropathy (nerve damage). Feet and legs are most often affected.

If nerve damage causes you to lose feeling in your feet, you could get a cut or blister and not know it.

Without treatment, a small sore can become a hard-to-heal infection that can threaten your health.

There are lots of other things you can do to protect your feet and keep them healthy:

- See a podiatrist (a foot care doctor).
- Check your feet (top and bottom) every day for calluses, cuts, sores, blisters and swelling.
- Wash your feet every day with warm water. Dry them well, especially between the toes.
- Keep the skin soft and smooth with lotion on the tops and bottoms of your feet (but not between your toes).
- Always wear shoes and socks or slippers—never go barefoot.
- Trim your toenails straight across.
- Get active in a foot-friendly way, like swimming or walking.

For more information and tips to keep your feet healthy: <https://bit.ly/2IIYE0s>

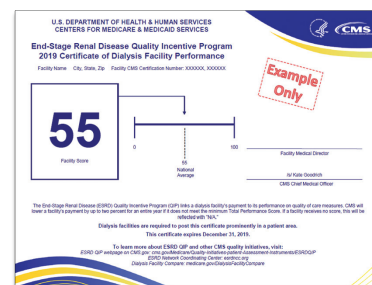
Medicare wants you to have Quality Dialysis Care

Medicare developed the Quality Incentive Program (QIP) to improve dialysis patient care by setting performance standards for quality of care.

Clinics who do not meet the standards may get a payment reduction of up to two percent. Each year the clinic will put up a new “Performance Score Certificate” for you to see how they are doing. You can also see the scores online on Dialysis Facility Compare.

Improving outcomes is a team effort. Your knowledge of the Quality Incentive Program can help with the clinic’s outcomes and keep them from getting a payment reduction.

You can make a big difference by being involved in making your Plan of Care and by following your diet, coming to every treatment and staying the entire time.



My Network:
QIP

Minutes Matter

The Risks of Shortening Treatments

It is very important that you receive your full dialysis treatments as your doctor has prescribed.

Coming for every treatment and staying for the full time is important in order to get the right amount of dialysis.

You may not think cutting treatment by 15 minutes or missing a treatment once a week makes a difference, but over time every minute adds up.

Some of the risks and possible complications from not getting enough dialysis are:

- Fluid overload. Too much fluid can cause shortness of breath and possible hospitalization.
- Severe cramping and low blood pressure (hypotension) at the next treatment because extra fluid will have to be removed.
- Missing injected medications can worsen anemia and bone disease.
- High potassium can cause heart problems, including irregular heartbeat, heart attack, and/or death.



My Treatment:
Am I Getting Enough Dialysis

Did You Know?

ESRD Network 12 works with:



Dialysis clinics to improve the care they give to patients throughout Iowa, Kansas, Missouri and Nebraska.



Patients to help when they have complaints about the care they get at their dialysis or transplant center.



Patients to make sure they get outpatient dialysis care.

We're here for you! For more information, contact us at:

800-444-9965



My Network

Be Opioid Aware

Patients deserve safe and effective pain treatment. But, opioid overdoses are rising very quickly.

Opioids are prescription pills used to treat pain. Examples include morphine, oxycodone, hydrocodone and illegal drugs like heroin. Every day, more than 1,000 people are treated in emergency departments for not using prescription opioids as directed.



Below are a few tips to keep you safe when your doctor wants you to take one of these pain pills.



Take only the amount prescribed.



Do not take opioids with alcohol.



Do not share or sell your opioids.



Never use someone else's opioids.



Store opioids securely out of reach of others.



Safely dispose of opioids. Ask your doctor or pharmacist for help.

For more information on how opioids work, risk when using them and other options to treat pain, visit www.beopioidaware.org.

TLC for Your Access

As your lifeline to get your dialysis treatment, it is very important that you take good care of your dialysis fistula or graft (access). Take care of your access by checking the following daily and often.



Touch

- For pulse
- For tenderness
- For temperature



Look

- At skin color
- For swelling
- For drainage



Care

- Keep clean
- Keep protected
- No resting on arm
- No heavy lifting
- No carrying
- Watch your weight
- Keep clothes loose
- No tight jewelry

Remember!



No blood pressure in access arm.



Only hemodialysis needles in access arm



Wash access before and after each dialysis treatment



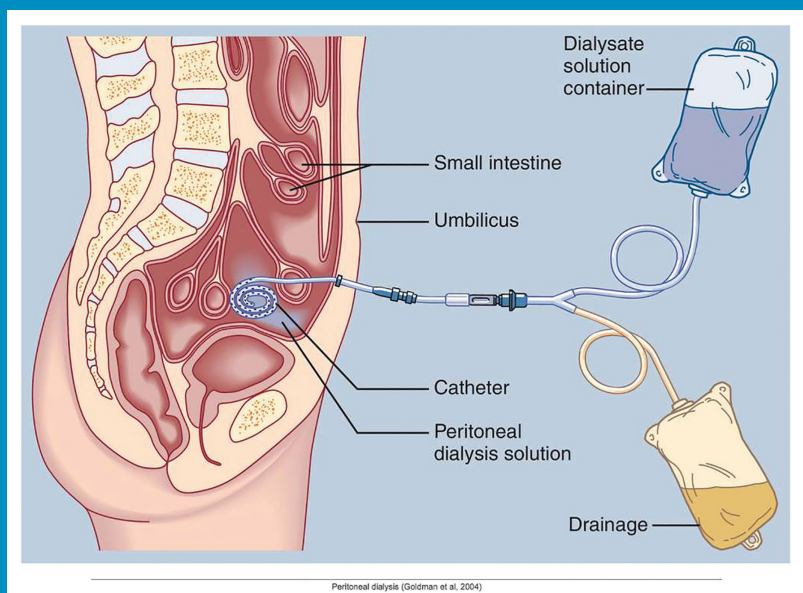
Wear gloves and mask during dialysis put-on and take-off

Peritoneal Dialysis (PD) Catheter Care

Taking good care of your catheter is important to prevent infections and do well on PD.

Here are some tips for routine catheter care:

- Check your catheter every day for signs of cracking or pulling.
- Do not wear tight clothes or belts around the exit site.
- Before handling your catheter and before and after an exchange is made, wash your hands with soap and water for at least two minutes and dry them with a disposable paper towel.
- Tape the catheter down to your skin.
- Keep the catheter away from scissors or other sharp objects.



- Cleanse the catheter thoroughly with a wash cloth and soap every day.
- Keep a special dressing over the exit site if your dialysis care team tells you to do so.
- Do not allow tugging or pulling of your catheter.

Let's Get Social

We're ready to connect with you!



If you "love" us, you have to "like" us on Facebook.

