

The one Star News etter

A Newsletter for People with Chronic Kidney Diseases and Their Families
Summer 2005

The End Stage Renal Disease Network of Texas, Inc.
14114 Dallas Parkway, Suite 660
Dallas, Texas 75254

Phone: 877-886-4435 or 972- 503-3215
www.esrdnetwork.org

Never Say Thirst, Say Dry Mouth !

Dialysis patients frequently complain about being thirsty. This is what makes you want to chew ice and drink so much water, which also accounts for all those pounds between dialysis treatments! Try as you may, you often feel like you will never quench your thirst. That's the point: you won't. Because it's not thirst.



What you feel is actually a dialysis **dry mouth**. As a matter of fact, real thirst among dialysis patients is rare! Suppose you and I are both “thirsty.” I have working kidneys so this means I have just been exercising strenuously. I am covered in perspiration and my mouth is bone dry. You, because your kidneys do not work, feel that way most of the time except you are not covered in perspiration. So we both drink a couple of tall glasses of water.

Fifteen minutes later you have that feeling again, but I do not. This is because my thirst was real thirst, which *can* be quenched. What you feel is dry mouth, which *cannot*. So you drink another glass of water. Thirty minutes later you still have that feeling and I am still satisfied. No matter how much water you drink, that feeling will not go away.

So, could it be real thirst? Maybe not. In fact, if you look at it from the point of view of your lungs and internal organs, your body may be closer to DROWNING than being thirsty. You may not *feel* like you're drowning. You feel more like you're dehydrating. In reality, about the only time most dialysis patients come close to dehydrating is toward the end of their dialysis treatment. Not a day or two afterwards! You may even *look* dehydrated, but you're not.

I recall a patient who went to the emergency room with nausea and shortness of breath. The emergency room physician swore he was dehydrated and ordered him to drink as much ice water as he could hold. [No, he never told the doctor he was on dialysis.] The patient knew he had at last found the doctor he had been looking for! A man who said drink all you want! It took three treatments in three days to get all the fluids off of him.

Maybe you could change your mind about thirst. You rarely experience genuine thirst. I know it feels like thirst, but it is dialysis dry mouth. And dry mouth does not require you to *swallow* water. With this in mind, it is easier to use all those tricks the dietitian taught you like brushing your teeth, eating an apple, chewing gum, breath mints, etc. Or you can swish some water around your mouth and (pardon) spit. It may be hard at first, but you can learn to have water in your mouth and not swallow. And remember, be smart about it.

Stop thinking thirst. Think dry mouth!

Dialysis Clinic Patient Representative Update

What is a Network Patient Representative (NPR)?

Each clinic is asked by the Network to appoint at least one **Network Patient Representative (NPR)** to be a contact person between the clinic patients and the Network. Some clinics have a Representative for each shift or each dialysis day. **We need more NPR's !** Here are some things an NPR may be asked to do:



Suggested *Standard* responsibilities include:

1. Be a role model to other patients by learning information about treatments for kidney disease and following his/her own treatment plan.
2. Receive and distribute ESRD Network patient mail- outs
3. At the clinic's request, communicate clinic updates or concerns to fellow patients
4. Be available to assist the staff with the patient bulletin board

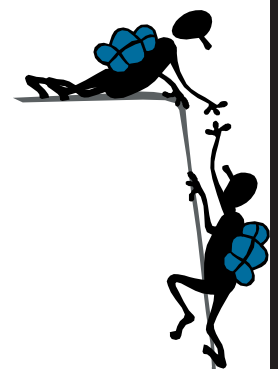
Suggested *Optional* responsibilities include:

1. Read and answer patients questions about information from their facility and the Network
2. Be available to:
 - Help with communications between patients and facility staff when needed or requested
 - Assist with the orientation and support of new patients
 - Assist the unit social worker with patient support groups
 - Assist with patient activities such as educational meetings and social events
 - Help organize phone calls or visits (where appropriate) to other patients
 - Write and distribute a patient newsletter for his/her own clinic with the aid of clinic staff

If you would like to assist the Network and your fellow patients with updates and information, then you are perfect for the job.

The Patient Advisory Committee (PAC) Your "Voice" at the ESRD Network

The PAC is a group of patients from around the state who give feedback to the Network staff and the Medical Review Board about issues that affect their care and quality of life. If you have a desire to make your issues known, you may contact Ramiro Valdez or Geli Brown at the ESRD Network at the toll- free number 877-886-4435.



2005 PAC Members

CHAIR: Karen Kennamer-Scott- Austin
VICE CHAIR: Jorge Garcia- McAllen
SECRETARY: Jennifer Kane- Houston
Freddy Cavazos- Corpus Christi
Gigi Cooper- Houston
Anna Gonzalez- San Antonio
Amy Hackney- Dallas

Edwin Hargraves- Mt. Vernon
Beverly Harrison- Haltom City
Cynthia Hays- Lubbock
Traci Neas- Houston
Brent Nichols- Victoria
Martin Ruiz- El Paso
Renaldo Smith- Fort Worth
Donise Sneed- Fort Worth

Who We Are ?

The End Stage Renal Disease Network of Texas (ESRD Network) is one of 18 not for profit agencies that work under contract with the Centers for Medicare & Medicaid Services (CMS) is the federal agency that runs Medicare. Your ESRD Network, which provides support to the Texas dialysis and transplant community, is located in Dallas, Texas. The other 17 Networks are located regionally across the country. The Networks perform many important jobs for the dialysis and transplant community, including:

- ✓ Collecting and analyzing data about dialysis and transplant patients and their treatments
- ✓ Evaluating the quality of care and services provided to dialysis and transplant patients
- ✓ Supplying professionals with clinical information and data they can use to evaluate and (if needed) improve their services
- ✓ Maintaining a grievance procedure to investigate patient complaints about the quality of care provided by dialysis or transplant units

The Network is made up of several volunteer committees-the Executive Committee, Medical Review Board, and Patient Advisory Committee. Each committee is made up of patients and professionals. The committees provide guidance and support to help the Network meet its mission and goals.

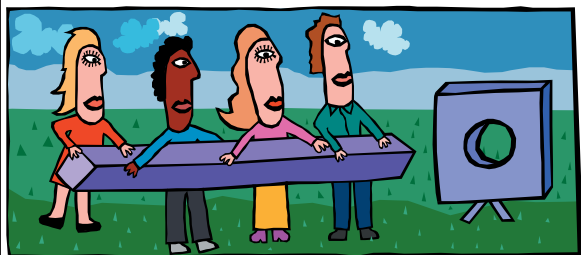
Our Goals

- ❑ To improve the quality of care for persons with ESRD and to make sure that this care is medically necessary, efficient, high quality and consistent with professional knowledge.
- ❑ To provide CMS, the Texas Department of State Health Services, and the dialysis and transplant community with information and data related to the Medicare ESRD program and the ESRD population.

How We **CAN** Help

*We **CAN** give you:*

- Information and advice to help you make informed decisions about your dialysis care or kidney transplant
 - Assistance in the prevention and resolution of concerns or grievances.
 - Information and data you can use to compare your clinical outcomes to Texas or national averages and to make professional recommendations.
 - Information on Medicare and Texas Department of State Health Services rules and regulations for dialysis and kidney transplant facilities.
 - ESRD data from Texas and the national dialysis and transplant community.
 - Names, locations, and services of facilities located in Texas and other Networks.
- A list of organizations that assist patients with educational literature and/ or financial support.



What We **CAN'T** Do

*We are **NOT** able to give you:*

- Answers to questions about bills (Medicare, Medicaid or insurance).
Contact Medicare at 800-442-2620.
- Financial help paying bills (Your facility social worker or administrator may be able to help you).
- Specific recommendations on doctors or clinics.
- Clinic or doctor specific data or outcomes.



??? What to do if you have a complaint ???

If you are unhappy with the care or treatment you receive at your dialysis clinic or transplant center, or if you have a complaint about your care, you have the right to file a complaint. **Here's how to file your complaint:**

- ❖ First-try to talk to your nurse, doctor, or social worker about the problem. It is possible there is a simple explanation. Even if there is not a simple explanation, it may be possible for you and the clinic to work out a solution to the problem that could result in better care for you and other patients.
- ❖ Next-if talking does not resolve the problem, or if you feel you cannot discuss your problem with the staff at your clinic, you can go directly to the regional administrator or even the corporate office of your dialysis company or transplant unit. The names and phone numbers of these people should be posted in the waiting room of your clinic.
- ❖ Finally-if none of the above actions work or if you feel your clinic or corporation cannot help you, call one of the Toll Free numbers below for help.

**Texas Department of
State Health Services
(877) 886-4435**

OR

**The ESRD Network of Texas
(888) 973-0022**

If you contact the Network for help WE CAN:

- ☺ Give you names and phone numbers of people you can speak to at your clinic's corporate offices.
- ☺ Give you information about Medicare regulations and your rights under Medicare.
- ☺ Contact the clinic and conduct a ***confidential*** investigation into your complaint, which may include one or more of the following actions:
 - Requesting medical records
 - Interviewing staff members or patients and asking for details about a complaint
 - If necessary, visiting a clinic in person
 - ***Confidential*** means we will not tell anyone at the facility or clinic your name, unless you give us permission to do so

If you contact the Network for help WE CANNOT:

- ⊗ Force a clinic or doctor to accept a patient.
- ⊗ Guarantee you can choose which staff members put your needles in.
- ⊗ Change or get involved in anything that has to do with personnel policies and procedures.
- ⊗ Get a doctor, nurse or patient care technician "fired" or transferred.

Network Employees and Positions

You may have heard of the ESRD Network of Texas but besides Ramiro Valdez, Director of Patient Services or Geli King-Brown, Outreach Coordinator, you may not know anything about the employees that perform the day-to-day duties of our organization. You may have heard their names mentioned at your clinic but did not know who they were or where they work. The Network has 11 full time employees and two part time employees. So you can become familiar with the different names you might hear at your clinic, we have listed the names, job titles and the job duties of each of the staff members. We have also listed on the bottom of the page our phone numbers and email address for your convenience. Our suggestion is to tear this page out of your newsletter and keep it by your telephone and computer for easy access. The Network staff is always ready to assist you and your family members with questions, educational materials, concerns and complaints.

Patient Services Department

Ramiro Valdez, PhD

Director of Patient Services

- Concerns/complaints/grievances
- Rehabilitation questions or issues
- Spanish Translation
- Patient Advisory Committee

Community Information and Resources

Geli King-Brown, MS

Outreach Coordinator

- Concerns/complaints/grievances
- Newsletters
- Dialysis & transplant resources, opportunities & educational materials
- Educational Meetings
- Patient Advisory Committee

Data Department

Nancy Carlson, MPA

Data Coordinator

Teri Griffin

Assistant Data Coordinator

Casey Contreras, Doris Wilson

Data Clerks

Administration Department

Glenda Harbert, RN, CNN, CPHQ

Executive Director

- Concerns or complaints about Network activities or Network personnel

Debbie O'Daniel

Office Manager

- Meeting registration/questions
- Booklet/pamphlet orders

Quality Improvement Department

Bobbie Knotek, BSN, CNN, CPHQ

Quality Improvement Director

Gay Grauke, BA

Project Coordinator

To contact the Network staff, you may call one of the following phone numbers:

Dallas area

972-503-3215

Outside the Dallas area

Toll Free Patient Hotline

1-877-886-4435

You can also address your questions or concerns to:

info@nw14.esrd.net



Have you ever wondered what Medicare does and does not pay for during the dialysis treatment?



The payment for each dialysis treatment is for the *whole* treatment. Medicare then pays 80% of their allowable amount. You may be required to pay the 20% not covered by Medicare. Under the Medicare rules the dialysis facility *must* provide the needed dialysis services, equipment and supplies listed in the left column below.

For patients receiving treatment in the dialysis center the facility must provide things like:	Medicare does not pay the dialysis facility for:
Gloves, emergency oxygen, dressing changes, removal of sutures (stitches), and staff time and equipment to do the dialysis, give blood transfusions, IV medications, and collection of laboratory specimens. <i>The dialysis facility may not ask you to pay for these things even if you need special supplies because of allergies.</i>	Drugs, supplies and oxygen for use at home. If you have another insurance company along with Medicare, the other company may pay for drugs, supplies and oxygen for home. Convenience items may be provided during dialysis such as pillows, blankets, TV's, radios, drinks, snacks at the facility's discretion <i>but these are not required items.</i>

Double Check Your Way To A Safe Dialysis Treatment

YOU should:


- Wash your hands and your access before going to your chair.
- Tell the charge nurse or doctor if you have concerns or questions about how you are feeling.
- Check your dialyzer to make sure it has your name on it (if your unit does re-use).

YOUR NURSE OR TECHNICIAN should:

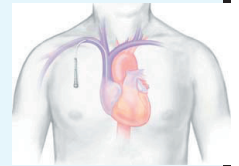
- Take your weight, temperature, heart rate and blood pressure and write them on your treatment sheet (or put them into the computer).
- Listen to the front and back of your chest with a stethoscope.
- Check your legs and feet for swelling.
- Ask you how you've been feeling and eating.
- Check that the right size needles and correct heparin dose are set up for your treatment.
- Check for residual sterilant in the dialyzer (if unit has reuse).
- Do a 2-person safety check of your dialyzer and write the results on your treatment sheet, or put them into a computer (if unit has reuse).
- Check your machine alarms, including the temperature and the conductivity. They should write the numbers down on your treatment sheet, or put them into a computer.
- Wash hands and put on new gloves before putting in your needles.



AFTER EVERY DIALYSIS TREATMENT: You should make sure:

- Your needle sites have stopped bleeding before trying to stand up.
 - You are strong enough to walk to the waiting room without getting dizzy or weak; don't rush to leave the clinic!
 - You weigh yourself wearing the same clothes, shoes, and jacket or sweater that you wore when you weighed before dialysis.
- 
- Ask if you have reached your dry weight. If you still have extra fluid, you may need to come back the next day for an extra treatment. If too much fluid is removed, you may need to get an IV or drink extra fluids.
 - Remember to take any prescriptions or educational materials with you.
 - Wash your hands if you held your access site to prevent the spread of germs.
 - Make sure the nurses are finished with you before you leave the clinic.

Are You Using a Catheter for Hemodialysis?



- If so, do you have a plan for a permanent access?
- Have you been using the catheter for 90 days or longer?
- Have you been told fistulas are better and safer accesses than catheters?
- Have you chosen not to get a fistula or another permanent access?

If you use a catheter for hemodialysis and your dialysis staff or kidney doctor have been encouraging you to change from a catheter to a fistula, you have probably received advice like this, *“You need to get a permanent access because catheters are dangerous; catheter complications can cause serious infections in the bloodstream and the heart.”*

Why do people with catheters want to keep using them, even when they know there is a high risk of catheter related illness or infection? Often it is because fear and anxiety about surgery, needles or changes in appearance get in the way of good decision-making. It’s not unusual to hear someone with a catheter say - *“I’m nervous about having surgery”*, *“What will my arm look like with a fistula?”* or *“I don’t want a fistula because I’m afraid of having needles put in my arm for dialysis.”* If you have fears and concerns about getting a fistula or other permanent access placed, there are things YOU can do to help decrease or overcome the fear and anxiety:

- ➔ Find out as much as you can about fistulas. Read stories written by people who have had fistulas for many years. A fun and interesting place to learn about vascular access is the Kidney School web site at www.kidneyschool.org.
- ➔ Talk to people in your facility using a fistula for dialysis. Ask them, *“What was the worst part of the experience? What are the benefits of having a fistula? Were you afraid of the needles – if so, how did you handle that? What do you tell people who ask about your fistula?”*
- ➔ If you are afraid of needles, ask your kidney doctor and dialysis staff for suggestions. Some people use anti-anxiety medicine or hypnosis. Others put their own needles in so they have control over how slow or fast the needles are put into the fistula.
- ➔ If you have had vascular access problems in the past and are afraid to “use up” another access site, ask your kidney doctor to refer you to a vascular access surgeon who *specializes* in people with complicated access placements.
- ➔ If you are worried about the surgery, ask your kidney doctor, surgeon or nurse to explain what will happen during the surgery. Will they put you to sleep? How long will the surgery take? How does the surgeon make the vascular access?

Did You Know?

- *Experts say people getting a permanent access should be evaluated for a fistula first.*
- *If for any reason a fistula is not possible, the experts say a graft is a safer access than a catheter for most people.*
- *Only about 10% of people on dialysis have to use a catheter for dialysis because there is no place to put a fistula or graft.*

Nutrition News

All about fluids:

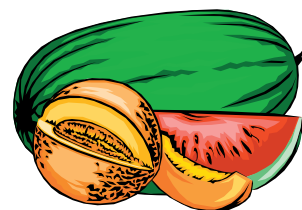


Water is important for your body to work but it is restricted for most kidney patients. The reason for the restriction is that most kidneys with renal failure don't make urine. This means that if you take in more fluid than you "put out", the fluid remains trapped in your body. This extra fluid may cause swelling, quick weight gain, high blood pressure, difficulty breathing, and even heart failure. Being short of breath can be a sign of having too much fluid in your body.

Here are some examples of fluids:

- Gelatin, Ice Cream or Sherbert
- Coffee, Water or Tea
- Snow Cones
- Liquids from vegetables (ex. green beans)
- Beer, wine and other alcoholic beverages (ask your doctor if you can drink these)
- Soup

Watermelon (1 cup = 1/2 cup of water)



Thirst can be related to hot weather, eating salty foods or adding salt to your meals. People with diabetes get thirsty when blood sugars run high. Also, there are medicines that can make your mouth feel dry.

Tricks for limiting your fluids!!!

- Plan your daily fluid intake. Remember 1 and 1/2 cups of ice melts down to 1 cup of water. Keep your fluids cold so you don't have to add ice.
- Drain the liquids from canned fruits and vegetables before serving them. Some foods, like cooked cereals and vegetables, have more liquid than others.
- Eat frozen fruits like grapes and strawberries.
- Keep track of your fluid intake. Check with your dietitian, doctor or nurse to find out how much fluid you should have in a day.
- Keep track of all fluids that you use to take medicines.

Remember, each person can have a different amount of fluid depending on how much urine they make

Your Dry Weight is your weight without extra fluids in your body.

This is your goal weight after dialysis. The weight you gain between treatments is **all fluid**. Talk to your dietitian, nurse and physician about how much fluid you can have everyday.



Recipes and Information

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Strawberry Ice Cream

Serves 6
 1/2 cup per serving

Ingredients:

- 1 10 oz package frozen sweetened strawberries
- 1 tablespoon lemon juice
- 1 cup crushed ice
- 3/4 cup non- dairy coffee creamer
- 1/2 cup sugar
- Few drops of red food coloring

Directions:

Thaw strawberries just until they break into chunks.
 Place all ingredients in a blender.
 Blend until smooth and sugar is dissolved.
 Pour into a covered dish.
 Freeze until firm.

Renal and Renal Diabetic
 Exchanges:
 1 Starch
 1 Low Potassium Fruit



What's in it for you?
 Calories: 144
 Carbohydrates: 28
 Protein: 1
 Fat: 3
 Sodium: 25
 Potassium: 108
 Phosphorus: 25

Lemon Curry Chicken Salad

Serves 4
 1 cup per serving

Ingredients:

- 1/4 oil
- 4 Tablespoons frozen lemonade concentrate, thawed
- 1/4 teaspoon ground ginger
- 1/4 ground curry powder
- 1/8-teaspoon garlic powder
- 1 1/2 cups chicken cooked and diced
- 1 1/2 cups grapes, halved
- 1/2 cup sliced celery

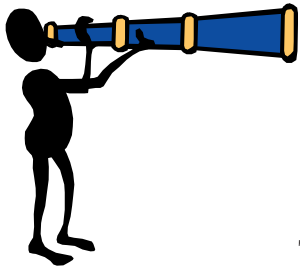
Directions:

In a large bowl, combine oil, lemonade concentrate and spices.
 Add remaining ingredients and toss lightly. Chill.



Renal and Renal Diabetic
 Exchanges:
 2 Meat
 1 Starch
 2 Fat

What's in it for you?
 Calories: 307
 Carbohydrates: 15
 Protein: 17
 Fat: 20
 Sodium: 57
 Potassium: 235
 Phosphorus: 119



What to look for in the upcoming months

Big Changes in Medicare: *Here comes Part D!*

The Centers for Medicaid & Medicare Services (CMS), in partnership with the Social Security Administration, will be sending you information about the new Part D Drug Prescription program that will begin January 1, 2006. This new program will replace existing discount drug programs that you may be using for discounts on your medicines.

Anyone receiving Medicare must sign up for this new program. There will be 2 different plan providers for Texas. Please read the information you receive on these providers very carefully so you know what each one is offering in their plans.

When you receive information in the mail on this new program don't throw it away! Bring the information to your social worker who can assist you. You will need to decide which provider is offering the best plan to meet your medicine needs.

The addition of Part D to the Medicare system will be a very big change in how everyone gets prescription medicines. **This will become your main source of drug coverage in place of The Kidney Health Care Program.** For more information, you can go online to the Medicare website at www.medicare.gov or you can call 1-800-MEDICARE.

Timeline of Dates:

October 2005: Information sent to Medicare patients

November 15, 2005: Open enrollment begins

January 1, 2006: Part D begins

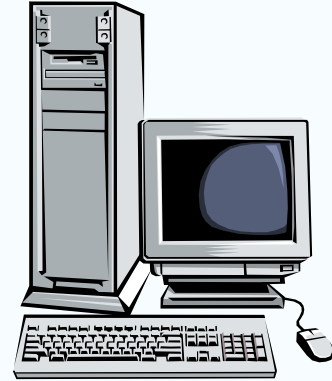
May 15, 2006: Open enrollment ends.

You must choose a provider and plan before this date or Medicare will choose a provider and plan for you!



Dialysis Facility Compare (DFC)

If you have access to a computer you can log onto www.medicare.gov and check out your dialysis facility. DFC allows you to look at services and how well the facilities in your state provide care. You can also read information from Medicare about kidney disease, coverage of dialysis and transplant and other topics.



Follow these steps once you log onto the CMS web site:



1. Go down to the bottom of the opening screen to Search Tools.
2. In the **Search Tools** section (on the left side), click on “Compare Dialysis Facilities in Your Area”
3. This will take you to the “welcome page” for Dialysis Facility Compare
4. Read the entire page for information on how to use the site



What information can you find on Dialysis Facility Compare?



- ❖ The percent of patients at a facility with URR of 65 or greater
- ❖ The percent of patients treated with Epogen that have a Hematocrit of 33 or greater
- ❖ Patient survival information

Information on a facility’s URR, anemia and patient survival is collected only for people on hemodialysis who receive Medicare benefits. Medicare is currently unable to collect this data for people who do not receive Medicare or who are on peritoneal dialysis.

- ❖ Date the facility received Medicare certification
- ❖ Address and phone number of the facility
- ❖ The number of dialysis treatment stations in the facility
- ❖ The type of dialysis services the facility offers
(in center hemodialysis, home hemodialysis and peritoneal dialysis)
 - Is there a dialysis shift starting at 5 p.m. or later?
 - Who owns the facility (profit or non-profit)?
 - Name of dialysis company that owns the facility (if that applies)

Resources and Important Numbers and Websites

American Association of Kidney Patients (AAKP)

800-749- AAKP www.aakp.org

AAKP is devoted to the needs, interests and concerns of dialysis and transplant patients as well as their families. There are four local chapters in Texas. To find out more about the Local chapter meetings, contact the president of each chapter (listed below). To find out how to start a chapter in your area call the National AAKP phone number listed above.

Lone Star	Space City	Dallas Fort Worth	Piney Woods
Tanya Randle	Vera Coleman- Foreman	Gene Bates	Edwin Hargraves
210-392-6337	713-272-7016	972-271-2057	903-537-7031
	aakp_spacecity@sbcglobal.net		edwinhargraves@webtv.net

Kidney School

www.kidneyschool.com

One of the BEST sources available for almost everything you need to know about kidney failure, dialysis and transplant. This site is organized into interactive, self-paced chapters.

American Kidney Fund

1-800-638-8299

www.akfinc.org

Bureau of Kidney Health

1-800-222-3986

www.dshs.state.tx.us/kidney

Medicare

1-800-813-8868

Customer Service Line

www.medicare.gov

United Network of Organ Sharing (UNOS)

1-800-292-9547

www.transplantliving.org

Texas Department of State Health Services (TDSHS)

1-888-973-0022

www.dshs.state.tx.us

The Renal Support Network (RSN)

1-818-543-0896

www.renalnetwork.org

We welcome articles or information that will be helpful to the ESRD patient community. To submit an article for consideration, call Geli King-Brown, Outreach Coordinator at 1-877-886-4435 or email gbrown@nw14.esrd.net.

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