Talking with Patients and Families about Kidney Disease

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Advancements in Diabetes Webinar

November 2023

Speaker has no relationship to disclose

Objectives

- Describe a strategy for educating people about CKD within the time constraints of the outpatient setting
- Describe life style and diet interventions which can slow progression of CKD
- Describe basic information about renal replacement therapy which can be provided prior to referral to nephrologist

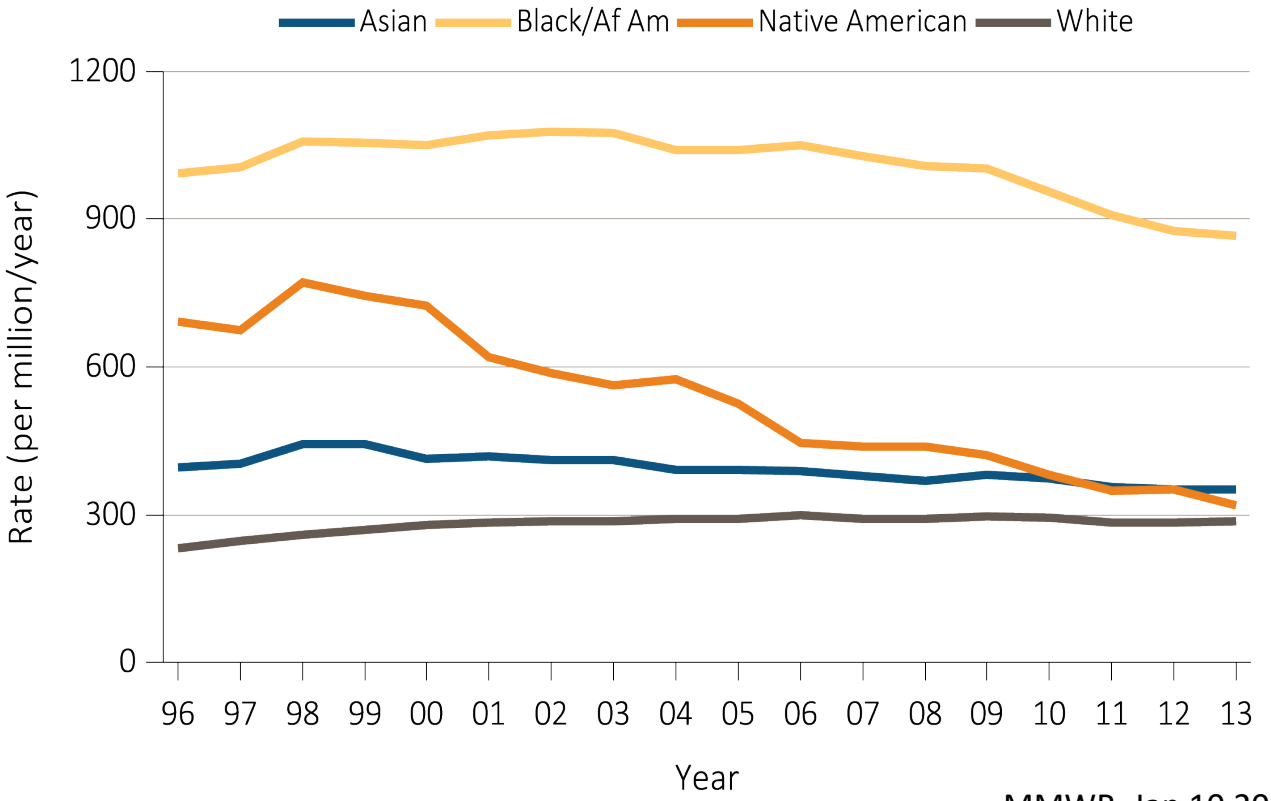
This is meant to be a pragmatic (useful) discussion. Specific questions welcomed.

Population Health in Kidney Disease

aims to reduce the morbidity and mortality caused by kidney disease and its complications by:

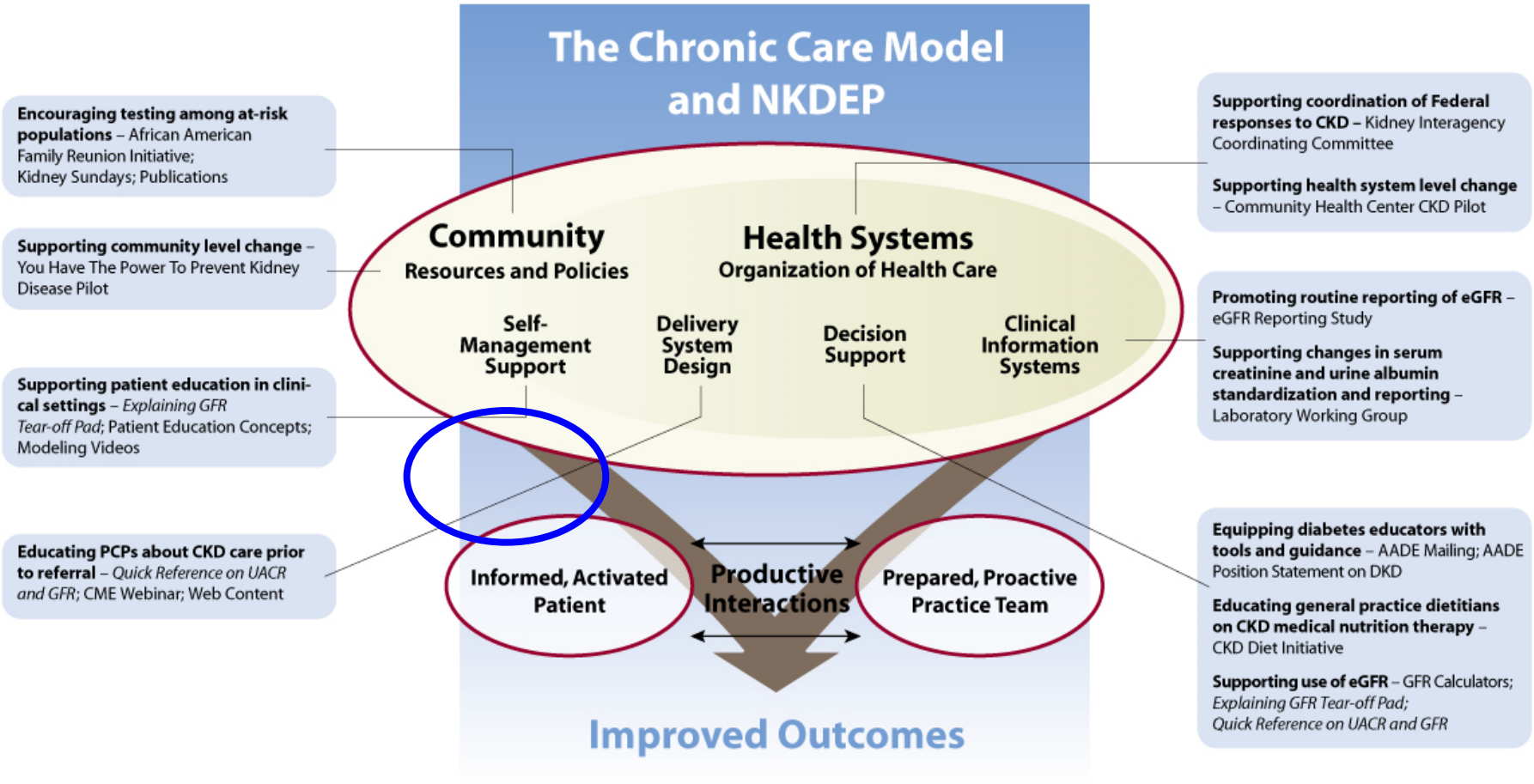
- Improving early detection of CKD
- Facilitating identification of patients at greatest risk for progression to kidney failure
- Promoting evidence-based interventions to slow progression of kidney disease

Trends in adjusted* ESRD incidence rate (per million/year), by race, in the U.S. population, 1996-2013



MMWR, Jan 10 2017

Education is Key



Goals for Population Management

Delay the need for renal replacement therapy (dialysis or transplant) :

- Identify patients with kidney disease and monitor progression: eGFR (kidney function) and UACR (kidney damage)
- Implement appropriate therapy to slow progression
- Screen for complications: anemia, malnutrition, metabolic bone disease
- Treat cardiovascular risk, especially with smokers and hypercholesterolemia
- Refer to dietitian for nutritional guidance
- Avoid acute injury to the kidney (NSAIDs)
- Educate patients about kidney disease and treatment

Self Management

- Self-management means the interventions, training, and skills by which patients with a chronic condition, disability, or disease can effectively take care of themselves and learn how to do so

http://en.wikipedia.org/wiki/Self-management

- Implementation of self management includes comprehensive education regarding the disease, management regimen, consequences of adherence, consequences of non-adherence

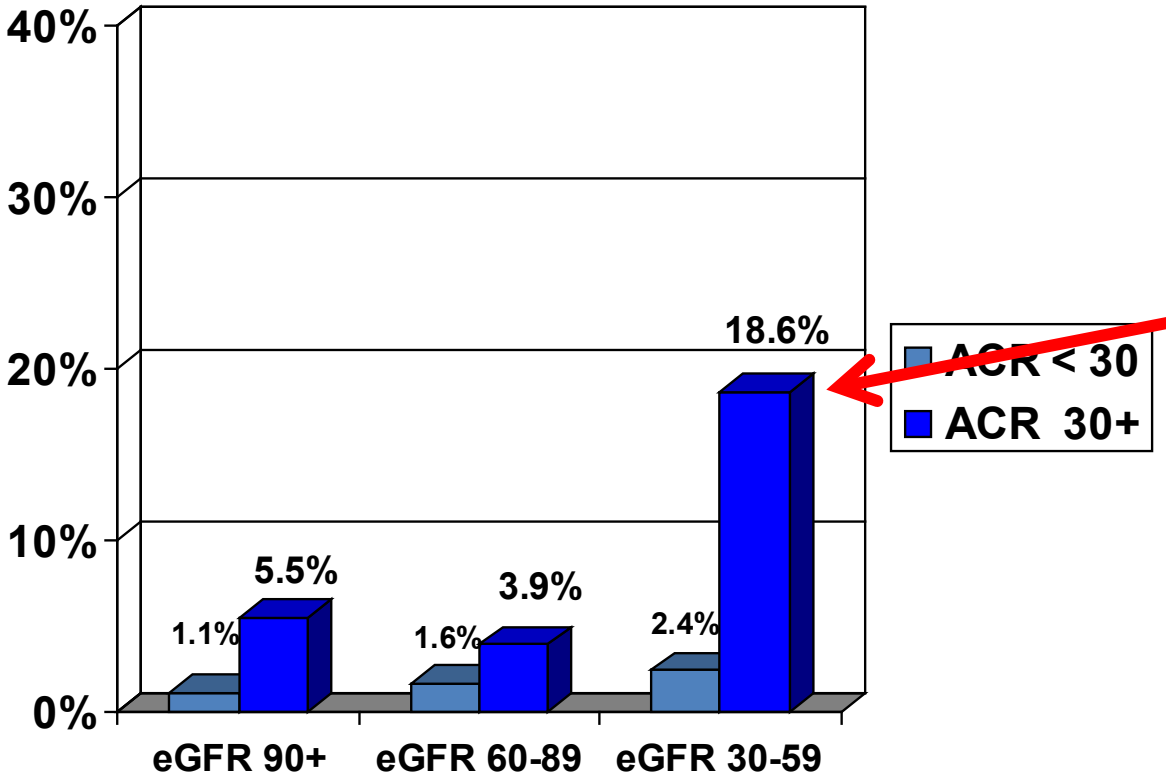
- Example of self-management in CKD: Knowing to stop ACEi or ARB if dehydrated from flu or diarrhia. Needs to occur before health care sought.

Coping with Kidney Disease and Failure is Challenging

- "I feel fine."
  - The signs and symptoms may not be obvious until kidney disease is advanced.
- "Why me?"
  - Just like diabetes, acceptance of kidney disease takes time for most people.
  - Kidney disease may progress to kidney failure.
- Kidney "failure" or "end stage renal disease" sound scary.
  - Grief, fear and depression are not uncommon.

Patient Awareness of CKD is Low General U.S. Population

"Have you ever been told by a doctor or other health care professional that you had weak or failing kidneys?"



NHANES 1999-2000:
4101 participants

< 20% of patients with moderate to severe CKD said yes

Most had seen a physician within the past year

Adapted from: Coresh, et al. JASN 2005

Awareness & Knowledge about CKD in Patients Seen by Nephrologists

Low Self-Rating Perceived Knowledge N=676	
No Knowledge of Hemodialysis / Peritoneal Dialysis	43% / 57%
Little or No Knowledge Re: Diagnosis	35%

Finkelstein, et al. Kidney International, 2008

Limited Awareness & Objective Knowledge N=401	
Unaware of CKD diagnosis	31%
Do not understand CKD implications, e.g. heart disease	34%
Do not understand kidney functions, e.g. urine production	34%
Do not understand terminology, GFR	32%

Wright, et al. AJKD 2011

Dialysis Patients and Their Providers Have Different Expectations

…patients' expectations about 1-year survival were more accurate than those of their nephrologists, but their longer-term survival expectations dramatically overestimated even their 2-year survival rates. Patients' prognostic expectations are associated with their treatment preferences. Our findings suggest the need for interventions to help providers communicate effectively with patients about prognosis.

Wachterman, et al. jama 2013

Educational Opportunities

- Community/At risk population
- People with CKD
- Health Care Providers

Quick Reference on UACR and GFR. FOR PROVIDERS

Urine Albumin-to-Creatinine Ratio (UACR)

In Evaluating Patients with Diabetes for Kidney Disease

The two key markers for chronic kidney disease (CKD) are urine albumin and estimated glomerular filtration rate (eGFR).

Assess urine albumin excretion yearly to diagnose *and* monitor kidney damage in patients with type 1 diabetes for five years or more or with type 2 diabetes.

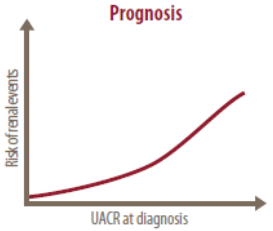
- More frequent monitoring may be indicated in patients with changing clinical status or after therapeutic interventions.
- Use a spot urine albumin-to-creatinine ratio (UACR). UACR estimates 24-hour urine albumin excretion. Twenty-four-hour collection and timed specimens are not necessary.

$$\frac{\text{Urine albumin (mg/dL)}}{\text{Urine creatinine (g/dL)}} = \text{UACR in mg/g} \approx \text{Albumin excretion in mg/day}$$

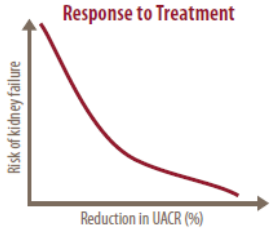
UACR is a ratio between two measured substances. Unlike a dipstick test for albumin, UACR is unaffected by variation in urine concentration.

Albuminuria[1] is present when UACR is greater than 30 mg/g and is a marker for CKD.

Albuminuria is used to diagnose and monitor kidney disease. Change in albuminuria may reflect response to therapy and risk for progression. A decrease in urine albumin may be associated with improved renal and cardiovascular outcomes.



In a large cohort of CKD patients, a higher UACR at time of diagnosis was associated with increased risk for renal events—loss of half of eGFR, dialysis, or death. (Chronic Renal Insufficiency Cohort study)



A randomized trial of diabetes patients with CKD found that the greater the reduction of UACR in response to treatment (with ARBs), the lower the risk of progression to kidney failure. (De Zeeuw D, et al. *Kidney International*, 2004:65:2309-2320)

[1]Albuminuria is a term that describes all levels of urine albumin. *Microalbuminuria* is a term used to describe urine albumin levels not detected by a dipstick test, i.e., 30 mg/g—300 mg/g. *Macroalbuminuria* is sometimes used to describe albumin levels more than 300mg/g.

Estimated Glomerular Filtration Rate (eGFR)

In Evaluating Patients with Diabetes for Kidney Disease

The two key markers for chronic kidney disease (CKD) are estimated glomerular filtration rate (eGFR) and urine albumin.

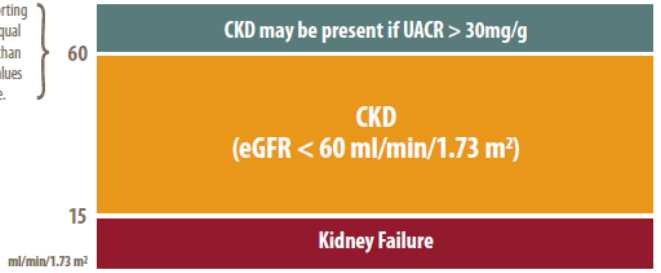
Calculate eGFR from stable serum creatinine levels at least once a year in all patients with diabetes.

- eGFR is more accurate than serum creatinine alone. Serum creatinine is affected by muscle mass, and related factors of age, sex, and race.
- eGFR is not reliable for patients with rapidly changing creatinine levels, extremes in muscle mass and body size, or altered diet patterns.

See if your lab reports eGFR routinely. If it does not, ask your lab to do so. You can also calculate an eGFR yourself by using GFR calculators available on NKDEP's website at *www.nkdep.nih.gov/professionals/gfr_calculators*.

Interpreting eGFR Results

NKDEP recommends reporting values greater than or equal to 60 as "≥60," rather than numeric values. Exact values above 60 are not reliable.



If CKD is detected, it should be addressed as part of a comprehensive approach to the treatment of diabetes.

For more information on UACR, eGFR, and kidney disease, go to *www.nkdep.nih.gov*.

The National Kidney Disease Education Program (NKDEP) of the National Institutes of Health aims to improve early detection of kidney disease, help identify patients at risk for progression to kidney failure, and promote interventions to slow progression of kidney disease.

NIH Publication No. 10-6286 • March 2010

U.S. Department of Health and Human Services
National Institutes of Health

NKDEP
National Kidney Disease Education Program

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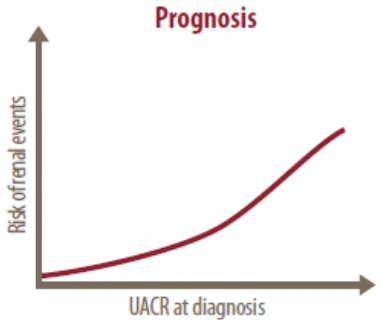

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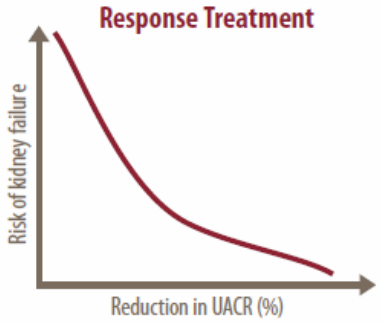

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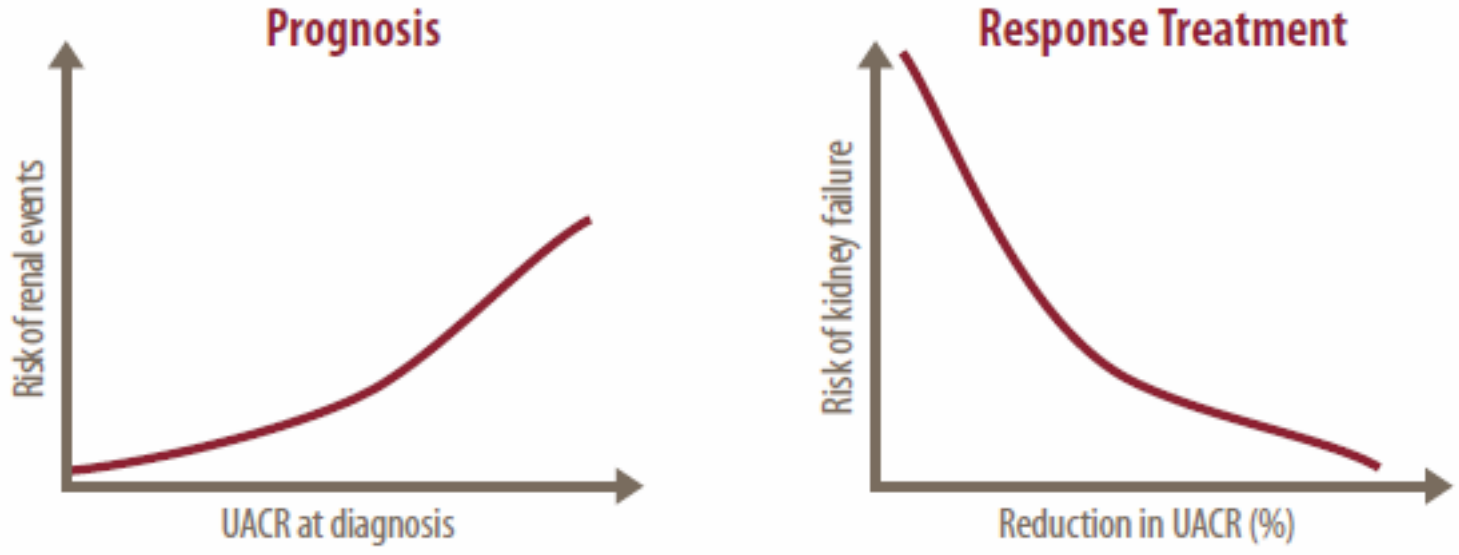
Elevated UACR is associated with risk of renal events; lowering UACR may lower risk of progression

Chronic Renal Insufficiency Cohort Study



Renal events = loss of half of eGFR, dialysis, or death

Reference: NIH, February 2010; De Zeeuw et al., 2004

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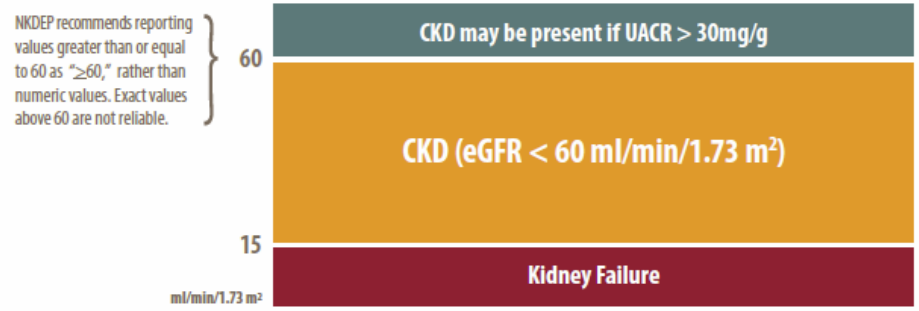

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NIH Publication No. 10-6286 • February 2010

U.S. Department of Health and Human Services
National Institutes of Health

NKDEP
National Kidney Disease Education Program

How well are your kidneys working?

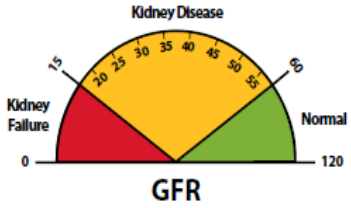
Explaining Your Kidney Test Results

Your GFR result on _____ was _____.
Date

☐ A GFR of *60 or higher* is in the normal range.

☐ A GFR *below 60* may mean kidney disease.

☐ A GFR of *15 or lower* may mean kidney failure.



What is GFR?

GFR stands for glomerular filtration rate. GFR is a measure of how well your kidneys filter blood.

Your urine albumin result on _____ was _____.
Date

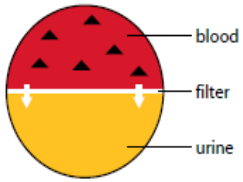
☐ A urine albumin result *below 30* is normal.

☐ A urine albumin result *above 30* may mean kidney disease.

What is urine albumin?

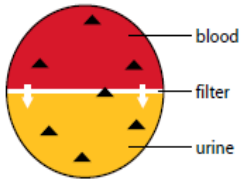
Albumin is a protein found in the blood. A healthy kidney does not let albumin pass into the urine. A damaged kidney lets some albumin pass into the urine. The less albumin in your urine, the better.

Inside a *healthy* kidney



▲ albumin

Inside a *damaged* kidney

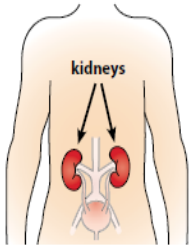


Your blood pressure result on _____ was _____.
Date

Keeping your blood pressure below 130/80 may help to protect your kidneys.

What your kidneys do

You have two kidneys. Their main job is to filter waste and extra water out of your blood and make urine.



How your kidneys are checked

Two tests are used to check for kidney disease.

- A blood test checks your GFR, which tells how well your kidneys are filtering.
- A urine test checks for albumin in your urine, a sign of kidney damage.

Why your kidneys are being checked

You need to have your kidneys checked because you can't feel kidney disease. Kidney tests are very important for people who have diabetes, high blood pressure, or heart disease. These conditions can hurt your kidneys.

What happens if you have kidney disease

Kidney disease can be treated. The sooner you know you have kidney disease, the sooner you can get treatment to help delay or prevent kidney failure. Treating kidney disease may also help prevent heart disease.

Treatment goals are to:

- Keep your GFR from going down
- Lower your urine albumin

No matter what your results are:

- Keep your blood pressure below 130/80.
- Keep your blood glucose and blood cholesterol in your target range.
- Eat foods that are healthy for your heart and cut back on salt.
- Be physically active.
- Stop smoking.
- Take medicines the way your provider tells you to.

Notes: _____

_____

_____

_____

For more information, visit *www.nkdep.nih.gov* or call 1-866-4 KIDNEY (1-866-454-3639). The National Kidney Disease Education Program (NKDEP) is an initiative of the National Institutes of Health (NIH).

NIH Publication No. 10-6220 • Revised January 2010

Explaining GFR

NKDEP
National Kidney Disease Education Program

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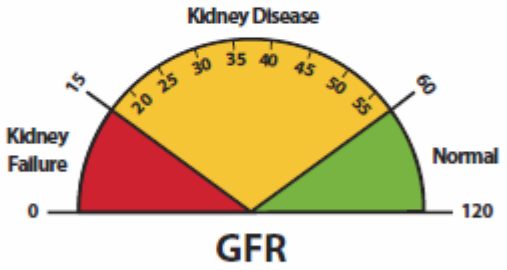

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Explaining Urine Albumin

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What is urine albumin?

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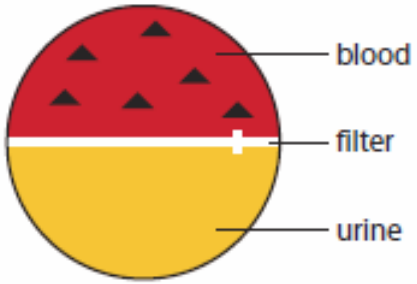
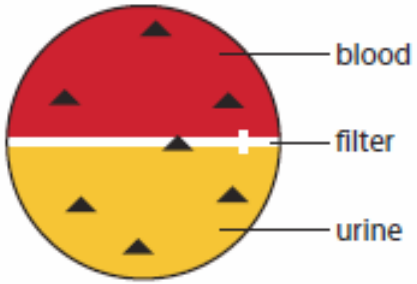
Inside a *healthy* kidney



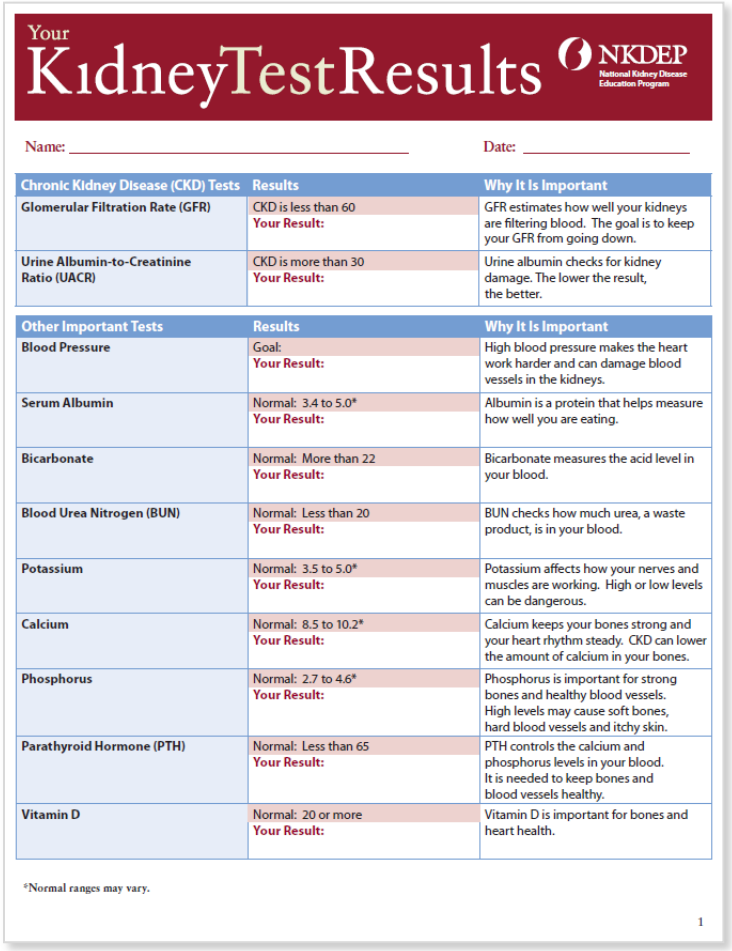
albumin

Inside a *damaged* kidney



Patient education--
Helping patients understand, track test results

- *Your Kidney Test Results* gives context for key kidney-related tests
  - Why test is important
  - Normal range
  - Multidisciplinary Provider Use



Your Kidney Test Results

NKDEP National Kidney Disease Education Program

Name: _____ Date: _____

Chronic Kidney Disease (CKD) Tests	Results	Why It Is Important
Glomerular Filtration Rate (GFR)	CKD is less than 60 Your Result:	GFR estimates how well your kidneys are filtering blood. The goal is to keep your GFR from going down.
Urine Albumin-to-Creatinine Ratio (UACR)	CKD is more than 30 Your Result:	Urine albumin checks for kidney damage. The lower the result, the better.

Other Important Tests	Results	Why It Is Important
Blood Pressure	Goal: Your Result:	High blood pressure makes the heart work harder and can damage blood vessels in the kidneys.
Serum Albumin	Normal: 3.4 to 5.0* Your Result:	Albumin is a protein that helps measure how well you are eating.
Bicarbonate	Normal: More than 22 Your Result:	Bicarbonate measures the acid level in your blood.
Blood Urea Nitrogen (BUN)	Normal: Less than 20 Your Result:	BUN checks how much urea, a waste product, is in your blood.
Potassium	Normal: 3.5 to 5.0* Your Result:	Potassium affects how your nerves and muscles are working. High or low levels can be dangerous.
Calcium	Normal: 8.5 to 10.2* Your Result:	Calcium keeps your bones strong and your heart rhythm steady. CKD can lower the amount of calcium in your bones.
Phosphorus	Normal: 2.7 to 4.6* Your Result:	Phosphorus is important for strong bones and healthy blood vessels. High levels may cause soft bones, hard blood vessels and itchy skin.
Parathyroid Hormone (PTH)	Normal: Less than 65 Your Result:	PTH controls the calcium and phosphorus levels in your blood. It is needed to keep bones and blood vessels healthy.
Vitamin D	Normal: 20 or more Your Result:	Vitamin D is important for bones and heart health.

*Normal ranges may vary.

1

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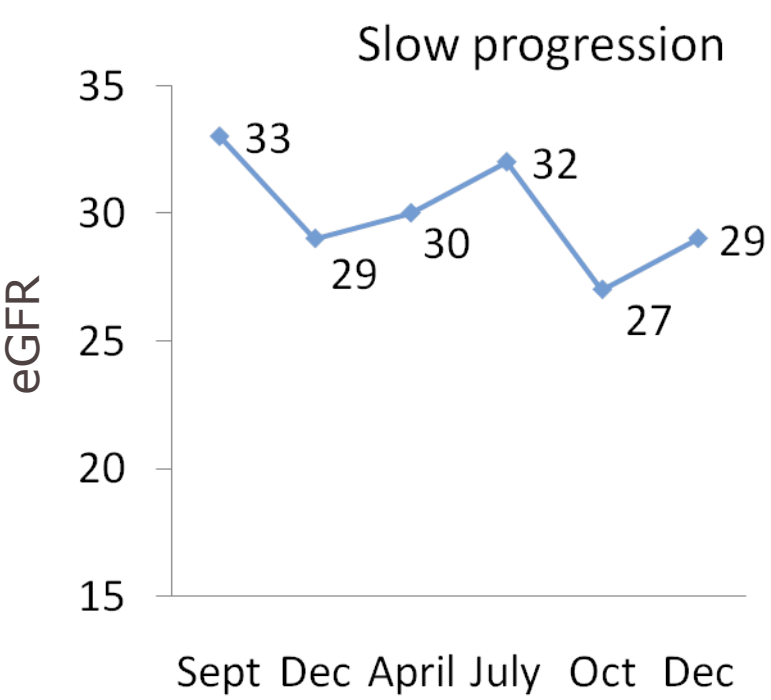
People with CKD still make urine

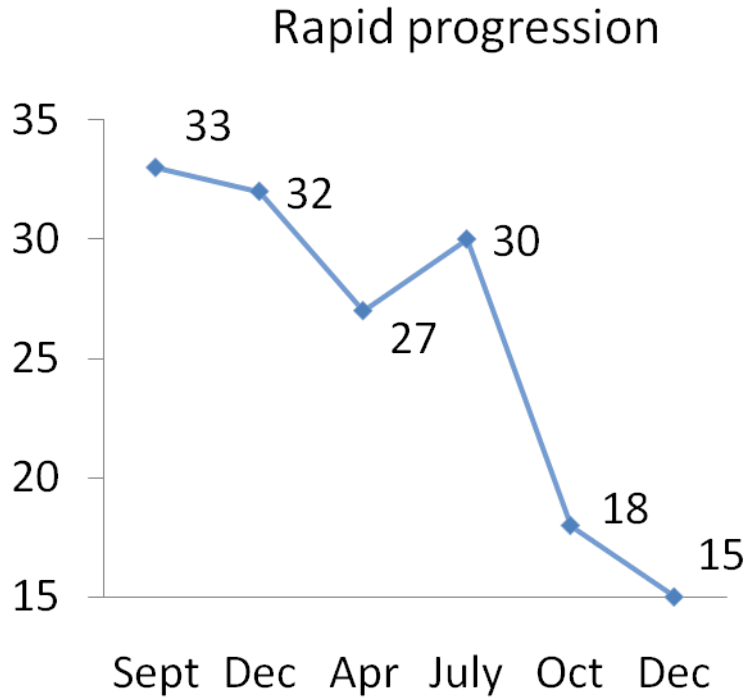
- The composition of the urine changes.
- Most people do not notice any difference in urine volume.
- Slow, progressive loss of function may not be noticeable.

Monitor the eGFR trends

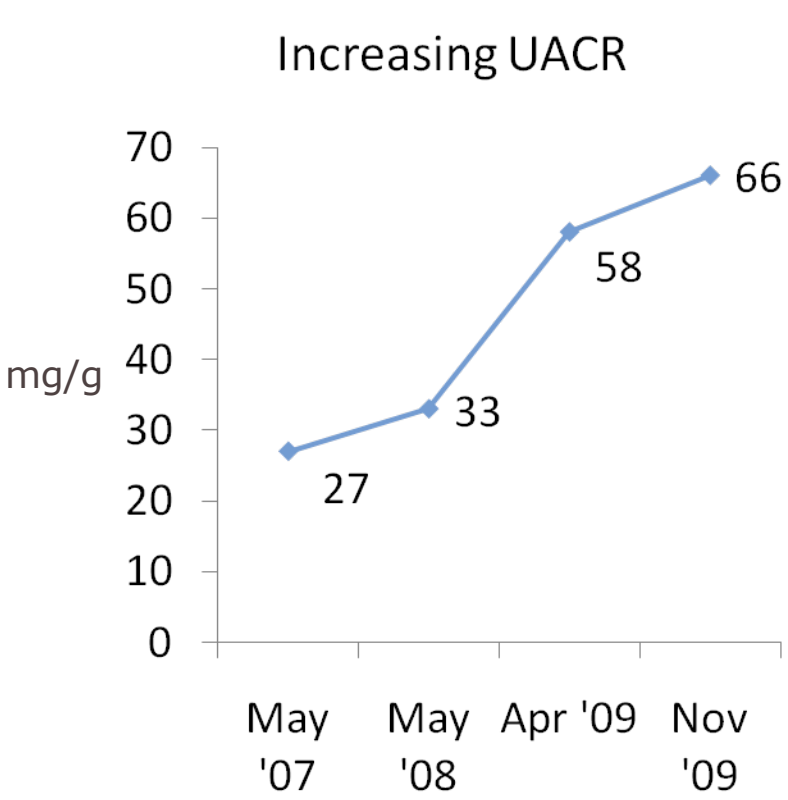
- Stable eGFR levels may mean non-progressive disease or current therapy is working.
- A rapid decline in eGFR may indicate rapid progression of kidney disease.

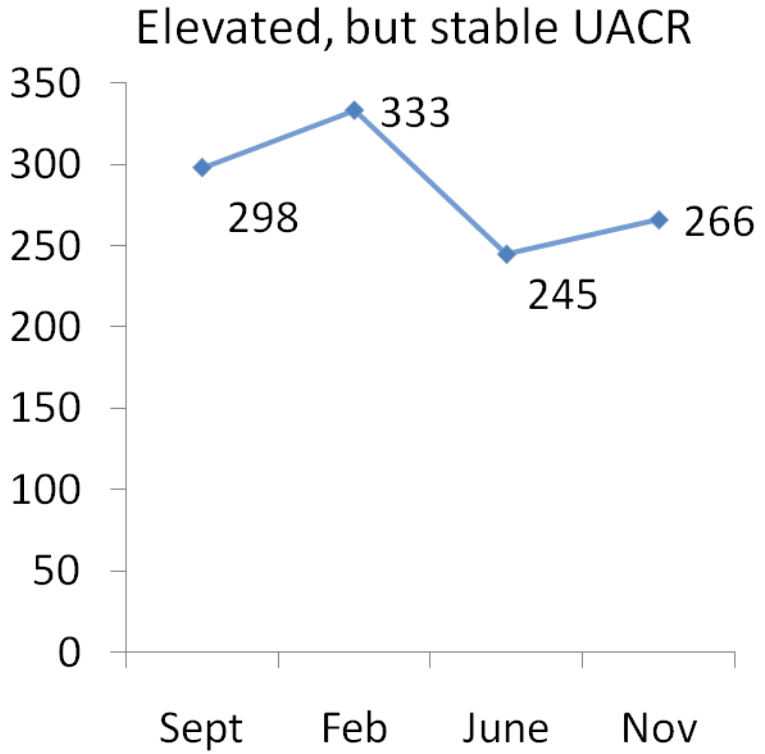
Follow trends in eGFR





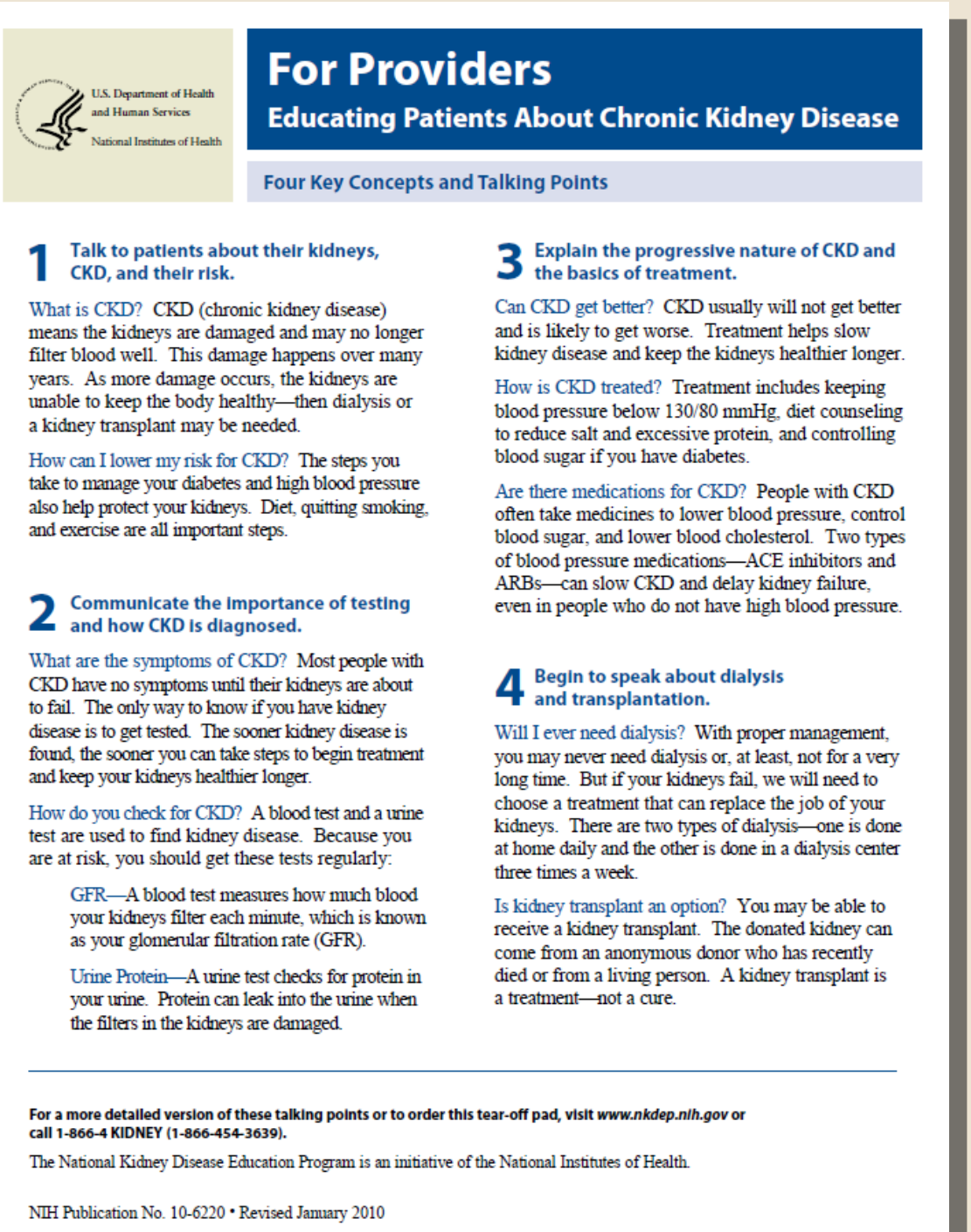
Follow trends in UACR





Note differences in timeframes

One page with simple explanations you can use as a starting point.



U.S. Department of Health and Human Services
National Institutes of Health

For Providers

Educating Patients About Chronic Kidney Disease

Four Key Concepts and Talking Points

1 Talk to patients about their kidneys, CKD, and their risk.

What is CKD? CKD (chronic kidney disease) means the kidneys are damaged and may no longer filter blood well. This damage happens over many years. As more damage occurs, the kidneys are unable to keep the body healthy—then dialysis or a kidney transplant may be needed.

How can I lower my risk for CKD? The steps you take to manage your diabetes and high blood pressure also help protect your kidneys. Diet, quitting smoking, and exercise are all important steps.

2 Communicate the importance of testing and how CKD is diagnosed.

What are the symptoms of CKD? Most people with CKD have no symptoms until their kidneys are about to fail. The only way to know if you have kidney disease is to get tested. The sooner kidney disease is found, the sooner you can take steps to begin treatment and keep your kidneys healthier longer.

How do you check for CKD? A blood test and a urine test are used to find kidney disease. Because you are at risk, you should get these tests regularly:

GFR—A blood test measures how much blood your kidneys filter each minute, which is known as your glomerular filtration rate (GFR).

Urine Protein—A urine test checks for protein in your urine. Protein can leak into the urine when the filters in the kidneys are damaged.

3 Explain the progressive nature of CKD and the basics of treatment.

Can CKD get better? CKD usually will not get better and is likely to get worse. Treatment helps slow kidney disease and keep the kidneys healthier longer.

How is CKD treated? Treatment includes keeping blood pressure below 130/80 mmHg, diet counseling to reduce salt and excessive protein, and controlling blood sugar if you have diabetes.

Are there medications for CKD? People with CKD often take medicines to lower blood pressure, control blood sugar, and lower blood cholesterol. Two types of blood pressure medications—ACE inhibitors and ARBs—can slow CKD and delay kidney failure, even in people who do not have high blood pressure.

4 Begin to speak about dialysis and transplantation.

Will I ever need dialysis? With proper management, you may never need dialysis or, at least, not for a very long time. But if your kidneys fail, we will need to choose a treatment that can replace the job of your kidneys. There are two types of dialysis—one is done at home daily and the other is done in a dialysis center three times a week.

Is kidney transplant an option? You may be able to receive a kidney transplant. The donated kidney can come from an anonymous donor who has recently died or from a living person. A kidney transplant is a treatment—not a cure.

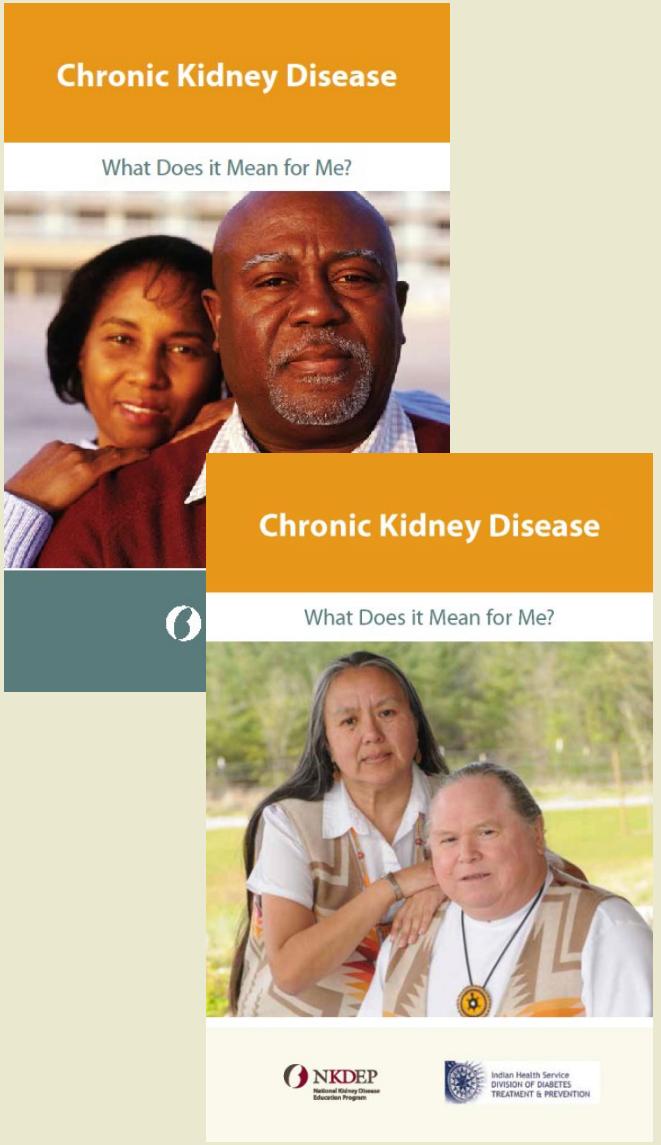
For a more detailed version of these talking points or to order this tear-off pad, visit *www.nkdep.nih.gov* or call 1-866-4 KIDNEY (1-866-454-3639).

The National Kidney Disease Education Program is an initiative of the National Institutes of Health.

NIH Publication No. 10-6220 • Revised January 2010

Explaining CKD to Recently Diagnosed Patients

- Brochure for recently diagnosed CKD patients
- Covers the basics:
  - Kidney anatomy
  - Causes of CKD
  - Medicines
  - Monitoring
  - Diet changes
  - Test results (and wallet card)
- 6th grade reading level



Questions to Ask if You Have Kidney Disease

Many people are afraid to learn that they have kidney disease because they think that all kidney disease leads to dialysis. However, most people with kidney disease will not need dialysis. If you have kidney disease, do not be afraid to ask your health care provider important questions about your health. The answers may help you prepare for treatment if you need it or ease your worries if you don't.

During your next health care visit, talk to your provider about your test results and how to manage your kidney disease. Below is a list of questions you may want to ask. Add any questions you think are missing, and mark those that are most important to you. Bring your list with you.

About your tests

- Did you check my kidney health with blood and urine tests?
- What was my GFR? What does that mean?
- Has my GFR changed since last time?
- What is my urine albumin level? What does that mean?
- Has my urine albumin changed since the last time it was checked?
- Is my kidney disease getting worse?
- Is my blood pressure where it needs to be?
- Will I need dialysis?
- When should I talk to my family about dialysis or a kidney transplant?

About treatment and self-care

- What can I do to keep my disease from getting worse?
- Do any of my medicines or doses need to be changed?
- Does what I eat need to change? Do my foods have the right amount of protein, salt (sodium),

What can I do?: Interventions for reducing urine albumin

- Control blood pressure
- Reduce sodium intake
- Achieve good control of diabetes early; may help prevent albuminuria
- Reduce weight (if obese)
- Reduce protein intake, if excessive
- Achieve tobacco cessation

Lifestyle modifications help lower blood pressure in the general population

Modification	Recommendation	Lowers Systolic Blood Pressure by (Range)
Weight reduction	•Maintain normal body weight •Body mass index (BMI) 18.5–24.9 kg/m^2	5–20 mm Hg / ↓ 10 kg ~ 4 mm Hg / ↓ 5 kg
DASH	•Increase potassium (fruits and vegetables) and calcium (dairy) •DASH may be too high in protein, potassium and phosphorus for CKD	8–14 mm Hg
Physical activity	•At least 30 minutes most days	4–9 mm Hg
Moderate alcohol consumption	•Women: ≤ 1 drink per day •Men: ≤ 2 drinks per day	2–4 mm Hg
Sodium restriction	•2,300 mg per day •1,500 mg per day for hypertension, diabetes, and CKD	2–8 mm Hg

Reference: Chobanian et al., 2003; Neter et al., 2003; Dietary Guidelines, 2010

Intentional weight loss is associated with decreased proteinuria

- Literature review showed weight loss was associated with decreased proteinuria.
  - Dietary restrictions
  - Exercise
  - Anti-obesity medications
  - Bariatric surgery
- No data to evaluate effect on CKD progression.

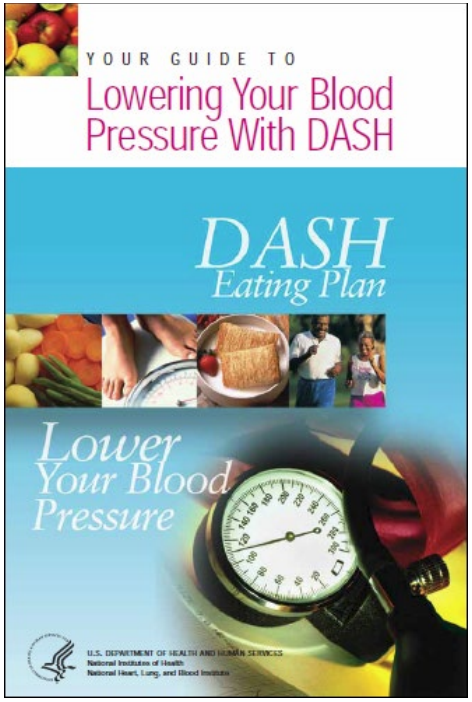
Reference: Afshinnia et al., 2010

Reducing sodium intake may reduce urine albumin levels

- In the Netherlands, higher sodium intake was associated with increased urine albumin excretion.
- In a 2006 literature review, increasing salt consumption was associated with worsening urine albumin.

Reference: Verhave et al., 2004; Jones-Jones-Burton et al., 2006

The DASH diet may help prevent CKD, but it is not generally used with CKD



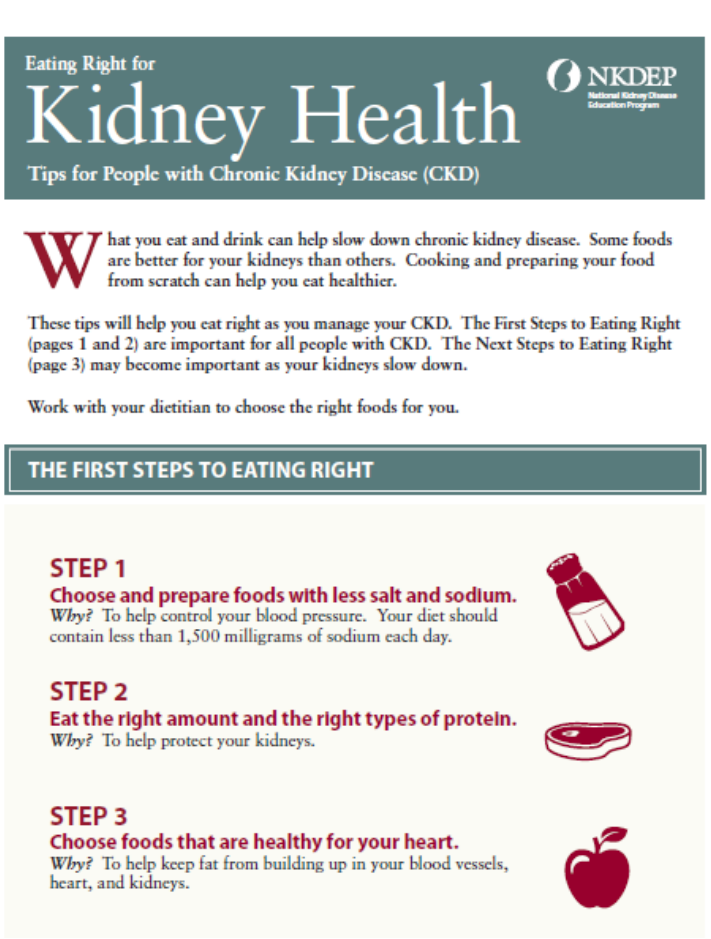
- The lower the sodium intake, the lower the blood pressure.
- Combining the DASH pattern and lowest sodium intake (1,150 mg) provided the greatest reduction in blood pressure.
- The DASH pattern *may* be too high in protein, potassium, and phosphorus for CKD.

References: Sacks et al. *N Engl J Med* 2001; 344(1):3–10 and http://www.nhlbi.nih.gov/health/public/heart/hbp/dash/new_dash.pdf

Common Barriers in Diet Counselling for Kidney Disease

- Recommendations too complicated
- Recommendations appear to contradict those for diabetes or CV risk reduction
- May assume that meals for patient will be prepared separately from remainder of family
- Emphasize expensive and difficult to access ingredients

An educational handout you can use to get started with diet changes



Eating Right for

Kidney Health

NKDEP National Kidney Disease Education Program

Tips for People with Chronic Kidney Disease (CKD)

What you eat and drink can help slow down chronic kidney disease. Some foods are better for your kidneys than others. Cooking and preparing your food from scratch can help you eat healthier.

These tips will help you eat right as you manage your CKD. The First Steps to Eating Right (pages 1 and 2) are important for all people with CKD. The Next Steps to Eating Right (page 3) may become important as your kidneys slow down.

Work with your dietitian to choose the right foods for you.

THE FIRST STEPS TO EATING RIGHT

STEP 1

Choose and prepare foods with less salt and sodium.

Why? To help control your blood pressure. Your diet should contain less than 1,500 milligrams of sodium each day.

STEP 2

Eat the right amount and the right types of protein.

Why? To help protect your kidneys.

STEP 3

Choose foods that are healthy for your heart.

Why? To help keep fat from building up in your blood vessels, heart, and kidneys.

Reference: http://www.nkdep.nih.gov/resources/nkdep-factsheet-overallpatient-508.pdf

Eating Right for Kidney Health

THE FIRST STEPS TO EATING RIGHT

STEP 1 Choose and prepare foods with less salt and sodium.

- Buy fresh food more often. Sodium (a part of salt) is added to many packaged foods.
- Use spices, herbs, and sodium-free seasonings in place of salt.
- Check the Nutrition Facts label on food packages for sodium. A Daily Value of 20% or more means the food is high in sodium.
- Try lower-sodium versions of frozen dinners and other convenience foods.
- Rinse canned vegetables, beans, meats, and fish with water before eating.

Look for Food Labels that Say
• Sodium free • Salt free • Very low sodium • Low sodium • Reduced or less sodium • Light in sodium • No salt added • Unsalted • Lightly salted

STEP 2 Eat the right amount and right types of protein.

- Eat small portions of protein foods.
- Protein is found in foods from plants and animals. Talk to your dietitian about how to choose the right combination for you.

Animal-protein Foods	Plant-protein Foods
• Chicken • Fish • Meat • Eggs • Dairy	• Beans • Nuts • Grains

STEP 3 Choose foods that are healthy for your heart.

- Grill, broil, bake, roast, or stir-fry foods, instead of deep frying.
- Cook with nonstick cooking spray or a small amount of olive oil instead of butter.
- Trim fat from meat and remove skin from poultry before eating.

Heart-healthy Foods
• Lean cuts of meat, like loin or round • Poultry without the skin • Fish • Beans • Vegetables • Fruits • Low-fat milk, yogurt, cheese

Eating Right for Kidney Health

THE NEXT STEPS TO EATING RIGHT

As your kidneys slow down, you *may* need to eat foods that are lower in phosphorus and potassium. Your health care provider will use lab tests to watch your levels.

STEP 4 Choose foods with less phosphorus.

Why? To help protect your bones and blood vessels.

- Many packaged foods have added phosphorus. Look for phosphorus—or for words with "PHOS"—on ingredient labels.
- Deli meats and some fresh meat and poultry can have added phosphorus. Ask the butcher to help you pick fresh meats without added phosphorus.

Foods *Lower* in Phosphorus	Foods *Higher* in Phosphorus
• Fresh fruits and vegetables • Breads, pasta, rice • Rice milk (not enriched) • Corn and rice cereals • Light-colored sodas/pop	• Meat, poultry, fish • Bran cereals and oatmeal • Dairy foods • Beans, lentils, nuts • Colas

STEP 5 Choose foods that have the right amount of potassium.

Why? To help your nerves and muscles work the right way.

- Salt substitutes can be very high in potassium. Read the ingredient label. Check with your provider about using salt substitutes.
- Drain canned fruits and vegetables before eating.

Foods *Lower* in Potassium	Foods *Higher* in Potassium
• Apples, peaches • Carrots, green beans • White bread and pasta • White rice • Rice milk (not enriched) • Cooked rice and wheat cereals, grits	• Oranges, bananas • Potatoes, tomatoes • Brown and wild rice • Bran cereals • Dairy foods • Whole wheat bread and pasta • Beans and nuts

Reference: http://www.nkdep.nih.gov/resources/nkdep-factsheet-overallpatient-508.pdf

The Transition from Chronic Kidney Disease to Kidney Failure

Dialysis or transplant are treatments, not cures.

Most People are Not Prepared for Kidney Failure

- Discuss treatment choices early with progressive kidney disease.
- “Early” depends on the eGFR and the rate of decline.
- People who are not prepared and need treatment do not have much choice. They may start hemodialysis using a temporary vascular access (catheter).
- In 2011, more than 80% of people started hemodialysis with a temporary vascular access.

Nephrologist May not be Best at Explaining Kidney Disease

CLINICAL RESEARCH www.jasn.org

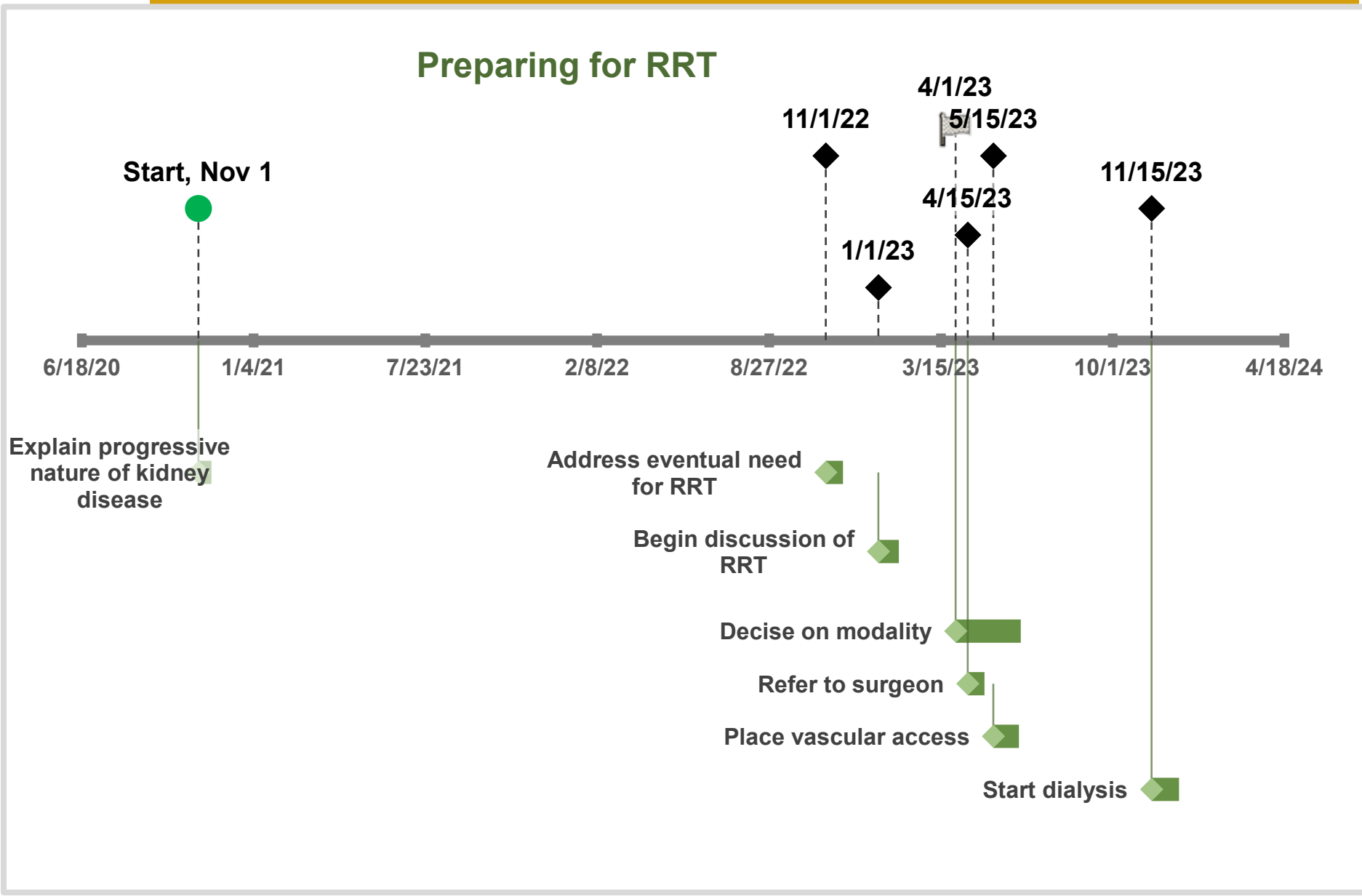
Nurse Practitioner Care Improves Renal Outcome in Patients with CKD

Mieke J. Peeters,*† Arjan D. van Zuilen,‡ Jan A.J.G. van den Brand,* Michiel L. Bots,§ Marjolijn van Buren,‖ Marc A.G.J. ten Dam,† Karin A.H. Kaasjager,¶ Gerry Ligtenberg,** Yvo W.J. Sijpkens,†† Henk E. Sluiter,‡‡ Peter J.G. van de Ven,§§ Gerald Vervoort,* Louis-Jean Vleming,‖ Peter J. Blankestijn,‡ and Jack F.M. Wetzels*

*Department of Nephrology, Radboud University Medical Center, Nijmegen, The Netherlands; †Department of Internal Medicine, Canisius Wilhelmina Hospital, Nijmegen, The Netherlands; ‡Department of Nephrology, University Medical Center Utrecht, Utrecht, The Netherlands; §Julius Center for Health Sciences and Primary Care, University Medical Center Utrecht, Utrecht, The Netherlands; ‖Department of Internal Medicine, Haga Hospital, The Hague, The Netherlands; ¶Department of Internal Medicine, Rijnstate Hospital, Arnhem, The Netherlands; **Dutch Health Care Insurance Board, Diemen, The Netherlands; ††Department of Nephrology, Leiden University Medical Center, Leiden, The Netherlands; ‡‡Department of Internal Medicine, Deventer Hospital, Deventer, The Netherlands; and §§Department of Internal Medicine, Maasstad Hospital, Rotterdam, The Netherlands

JASN February 2014 25: 390-398

OMG! Talk to patients about dialysis!?!?!?



It is OK to discuss treatment options early

- Discuss options early with patients with progressive CKD, give them time to prepare. It will never be "OK" to have kidney failure.
- Patients diagnosed with kidney "failure" or *loss* of kidney function may experience grief, fear, or depression.
- By discussing early you are giving the patient time to process and understand.
- Include family members if possible. They will be part of the patients treatment.
- The "diet" will change; and changes depend on the chosen option.
- Consider using a skilled translator. English may not be the best option to explain a disease which is complicated and scary.

An informed patient is better prepared

- Consistent messages are better.
- Providers should be teaching the same thing.
- Education may help patients to be successful in their self-management efforts.

- However, many materials which are available assume a level of health literacy which is above that of people at greatest risk of progressive disease.

Preparing for Kidney Failure Treatment

As your kidney disease progresses, your health care provider may talk to you about preparing for kidney failure. Talking with your provider about your treatment options ahead of time helps you take charge of your care. Treatment will help you feel better and live longer. The more you know about the types of treatment, the better prepared you may be to make a choice. It's also important to give yourself time to get used to the big changes that will be happening in your life.

Learn about steps you can take ahead of time to have better success with dialysis or a kidney transplant.

Preparing for Hemodialysis: Vascular Access

If hemodialysis is the best option for your treatment, one important step before starting treatment is creating a vascular access. Vascular access is the term for how blood can be removed from your body and returned at the high rate that dialysis requires. The goal is to allow high blood flow during dialysis treatment so that the largest amount of blood can be passed through the dialyzer (artificial kidney). Your own veins are not large enough to be used for dialysis. The best kind of long-term vascular access for hemodialysis is an arteriovenous (AV) fistula. An AV fistula is created when a surgeon connects an artery to a vein, usually in the arm. The increased blood flow through the AV fistula causes the vein to grow large and strong allowing the needles used for dialysis to be easily placed in the blood vessels. The AV fistula is considered the best option because it:

- provides adequate blood flow for dialysis,
- lasts longer, and
- has a lower complication rate than the other types.

If an AV fistula cannot be created, the two other kinds of vascular access that may be used are an AV graft or venous catheter. An AV graft is a connection from an artery to a vein using a synthetic tube. An AV graft can be used soon after it is inserted. However, an AV graft is more likely than a fistula to have problems with infection and clotting, and the repeated formation of blood clots can block the flow of blood through the graft.

Vascular access should be in place weeks or months before you start dialysis. Learn more about vascular access and fistulas.

KIDNEY FAILURE

- Overview
- Dialysis
- Kidney Transplant
- Preparing for Kidney Failure Treatment

Videos

DIALYSIS & TRANSPLANTATION
Why is a fistula the best option? ›

DIALYSIS & TRANSPLANTATION
What should I do to prepare for surgery? ›

See more videos

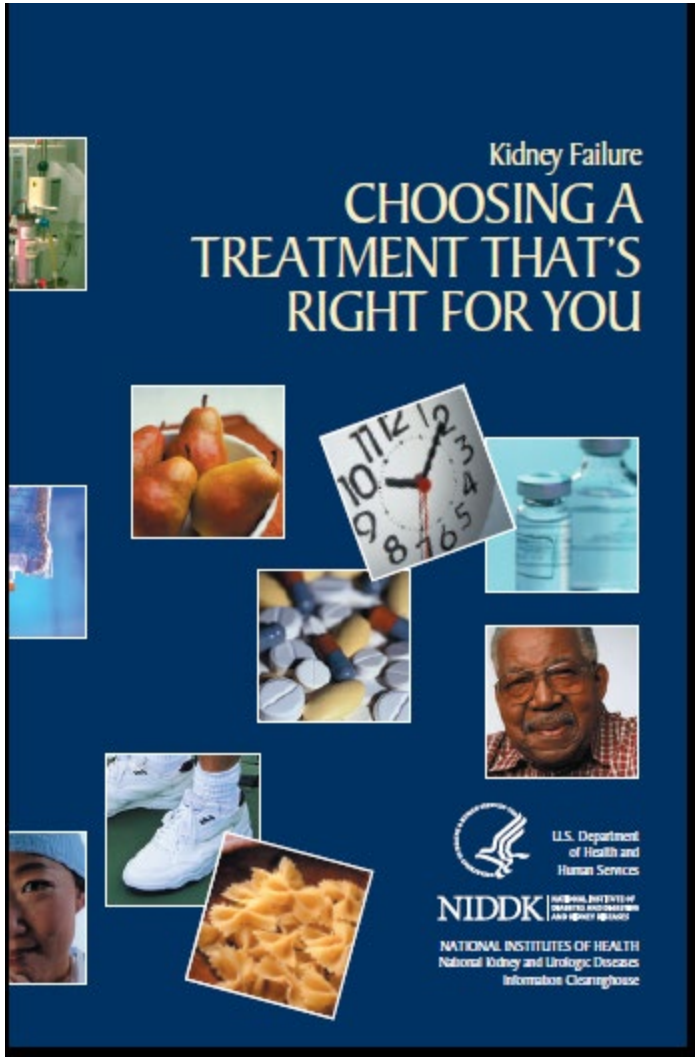
Kidney disease education is a Medicare benefit

- eGFR < 30
- Medicare B
  - Individual pays 20%, deductible applies
- Qualified providers: physicians, physician assistants, nurse practitioners, and clinical nurse specialists
- Up to six sessions covered

Equipping educators with lesson plans using sources which do not require high health literacy and are in the public domain

- *Kidney Disease Education Lesson Builder* helps educators create and deliver educational sessions for patients with CKD on managing the disease and preparing for RRT
- Supports CMS KDE benefit

https://www.niddk.nih.gov/health-information/professionals/education-cme/kidney-disease-education-lesson-builder



Reference: http://kidney.niddk.nih.gov/kudiseases/pubs/pdf/choosingtreatment.pdf

Four options for treating kidney failure

- Renal replacement therapy (RRT)
  1. Hemodialysis
     - In-center or home, three times a week or more frequently
  2. Peritoneal dialysis
     - Daily, at home
  3. Kidney transplantation
- No RRT
  4. Conservative management
     - Active medical management

Conservative management is active medical management with no RRT.

- No non-dialysis way can replace loss of clearance of uremic toxins.
- Complications can be treated.
- Continue medications.
- Provide comfort and palliative care.
- Encourage patient to inform family.
- This may be a better choice for some patients where RRT has not been shown to increase quality or quantity of life.
  - Feels treatment will not improve their health.
  - Feels they have done what they wanted to do in life.
  - Has family and friends who are in support of this decision.

Summary: treatment options

- Discuss the options early to allow time for the patient to adjust and make a decision.
- The diet will change with dialysis, more protein is needed to replace the losses.Hemodialysis has the most restrictive diet.
- Transplant requires daily immunosuppressant medication.
- All the options still require medications.
- Shared Decision Making Materials available

Shared and Informed Decision-Making (SDM) to Improve Renal Replacement Therapy Preparation

- "Decisions that are shared by doctor and patient and informed by best evidence, not only about risks and benefits, but also about patient-specific characteristics and values"[1]
  - Physician competencies and patient competencies
  - Family also important in decisions about renal replacement therapy
- Goals of SDM in late stage progressive CKD
  - Engage in self-management to slow CKD progression
  - Engage in preparation for renal replacement therapy

1: Towle A, Godolphin W. Framework for teaching and learning informed shared decision-making. BMJ. 1999; 7212:766-9

Shared Decision Making

Evidence on differences between treatment choices

Preparing for Kidney Treatment
You Have a Choice

Preparándose para el tratamiento de riñón
Usted tiene opciones

El tratamiento que yo escoja, ¿afectará qué tan bien puedo movilizarme?

Podría afectar.

El trasplante puede ser más o menos igual o mejor que la diálisis peritoneal.

Clasificación de los estudios ★★★★

El trasplante puede ser más o menos igual o mejor que la hemodiálisis realizada en un centro.

Clasificación de los estudios ★★★★

La diálisis peritoneal puede ser más o menos igual que la hemodiálisis realizada en un centro.

Clasificación de los estudios ★★★★

El trasplante puede ser más o menos igual o mejor que la diálisis peritoneal.

Los estudios muestran que algunas personas en diálisis peritoneal se movilizan igual de bien que las personas con trasplante. Otras personas en diálisis peritoneal se movilizan mucho peor.

Aquí está lo que mostró un estudio:

El trasplante puede ser más o menos igual o mejor que la hemodiálisis realizada en un centro.

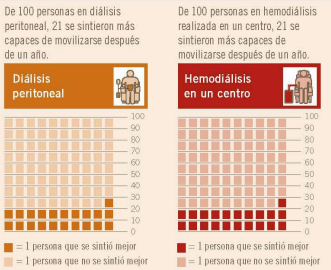
Los estudios muestran que algunas personas en hemodiálisis se movilizan igual de bien que las personas con trasplante. Otras personas en hemodiálisis se movilizan mucho peor.

Aquí está lo que mostró un estudio:

La diálisis peritoneal puede ser más o menos igual que la hemodiálisis realizada en un centro.

Los estudios muestran que precisamente la misma cantidad de personas en cada tratamiento se siente más capacitada para movilizarse a medida que pasa el tiempo.

Aquí está lo que mostró un estudio:



Will my treatment choice affect how free I feel to do things?

It could.

Transplant may be better than peritoneal dialysis.

Studies' Rating ★★★★

Transplant may be better than in-center hemodialysis.

Studies' Rating ★★★★

In-center hemodialysis may be about the same or better than peritoneal dialysis.

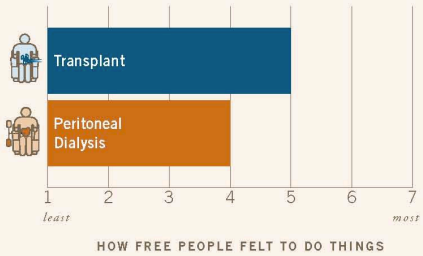
Studies' Rating ★★★★

Transplant may be better than peritoneal dialysis.

Studies show some people on peritoneal dialysis feel a little less free to do things than people with a transplant. Others on peritoneal dialysis feel a lot less free.

Here's what one of these studies showed:

In one study, people with a transplant felt freer to do things than people on peritoneal dialysis.

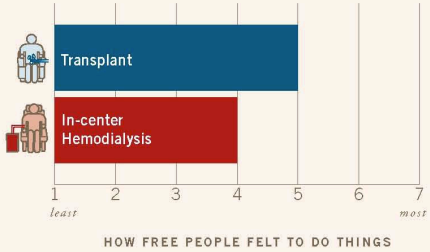


Transplant better than in-center hemodialysis.

Studies show some people on hemodialysis feel somewhat less free to do things than people with a transplant. Others on hemodialysis feel a lot less free.

Here's what one of these studies showed:

In one study, people with a transplant felt freer to do things than people on hemodialysis.

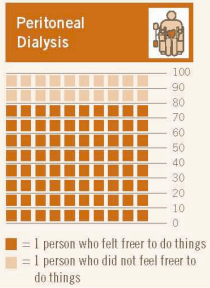


In-center hemodialysis may be about the same or better than peritoneal dialysis.

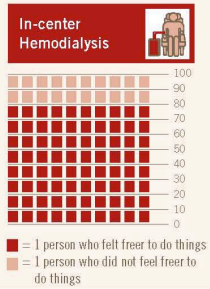
Studies show some people on peritoneal dialysis feel just as free to do things as people on hemodialysis. Others on peritoneal dialysis feel a little less free.

Here's what one of these studies showed:

80 out of 100 people on peritoneal dialysis felt freer to do things after one year.



80 out of 100 people on in-center hemodialysis felt freer to do things after one year.



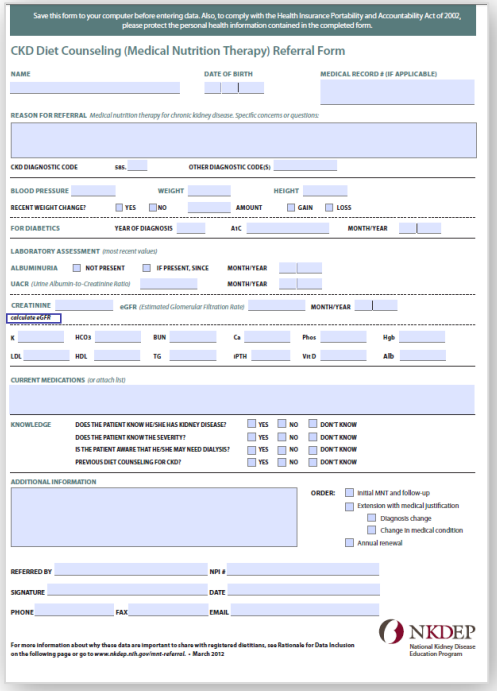
PREPARED Video And Books (English and Spanish)

Website in transition= check back later

Facilitating collaborative management to improve patient outcomes

- For use by referring primary care providers to share key patient data
- Enter patient information – save, email, or print

CKD Diet Counseling Referral Form



Save this form to your computer before entering data. Also, to comply with the Health Insurance Portability and Accountability Act of 2002, please protect the personal health information contained in the completed form.

CKD Diet Counseling (Medical Nutrition Therapy) Referral Form

NAME | DATE OF BIRTH | MEDICAL RECORD # (IF APPLICABLE)

REASON FOR REFERRAL *Medical nutrition therapy for chronic kidney disease. Specific concerns or questions:*

CKD DIAGNOSTIC CODE | stage | OTHER DIAGNOSTIC CODE(S)

BLOOD PRESSURE | WEIGHT | HEIGHT

RECENT WEIGHT CHANGE? YES NO | AMOUNT | GAIN LOSS

FOR DIABETICS | YEAR OF DIAGNOSIS | A1C | MONTH/YEAR

LABORATORY ASSESSMENT *(most recent values)*

ALBUMINURIA NOT PRESENT IF PRESENT, SINCE MONTH/YEAR

UACR *(Urine Albumin-to-Creatinine Ratio)* | MONTH/YEAR

CREATININE | eGFR *(Estimated Glomerular Filtration Rate)* | MONTH/YEAR

calculate eGFR

K | HCO3 | BUN | Ca | Phos | Hgb

LDL | HDL | TG | iPTH | Vit D | Alb

CURRENT MEDICATIONS *(or attach list)*

KNOWLEDGE

DOES THE PATIENT KNOW HE/SHE HAS KIDNEY DISEASE? YES NO DON'T KNOW

DOES THE PATIENT KNOW THE SEVERITY? YES NO DON'T KNOW

IS THE PATIENT AWARE THAT HE/SHE MAY NEED DIALYSIS? YES NO DON'T KNOW

PREVIOUS DIET COUNSELING FOR CKD? YES NO DON'T KNOW

ADDITIONAL INFORMATION

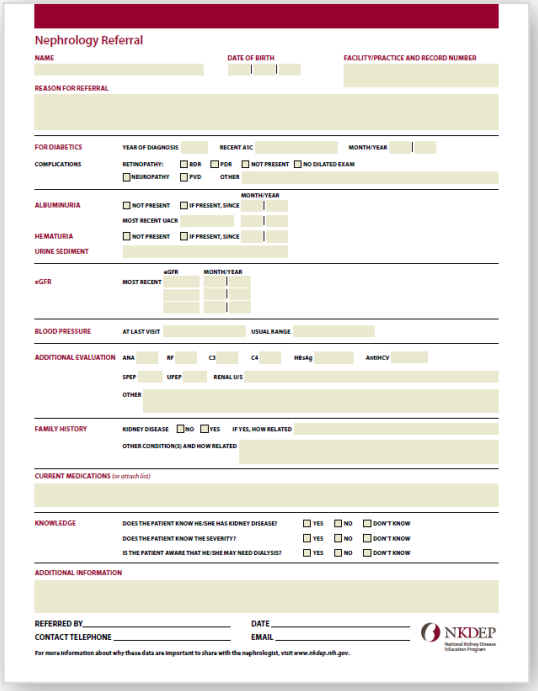
ORDER:
- Initial MNT and follow-up
- Extension with medical justification
  - Diagnosis change
  - Change in medical condition
- Annual renewal

REFERRED BY | NPI # | SIGNATURE | DATE | PHONE | FAX | EMAIL

For more information about why these data are important to share with registered dietitians, see Rationale for Data Inclusion on the following page or go to www.nkdep.nih.gov/mnt-referral. • March 2012

NKDEP National Kidney Disease Education Program

Nephrology Referral Form



Nephrology Referral

NAME | DATE OF BIRTH | FACILITY/PRACTICE AND RECORD NUMBER

REASON FOR REFERRAL

FOR DIABETICS | YEAR OF DIAGNOSIS | RECENT A1C | MONTH/YEAR

COMPLICATIONS | RETINOPATHY: BDR PDR NOT PRESENT NO DILATED EXAM | NEUROPATHY PVD OTHER

ALBUMINURIA | NOT PRESENT IF PRESENT, SINCE MONTH/YEAR

MOST RECENT UACR

HEMATURIA | NOT PRESENT IF PRESENT, SINCE

URINE SEDIMENT

eGFR | MOST RECENT | eGFR | MONTH/YEAR

BLOOD PRESSURE | AT LAST VISIT | USUAL RANGE

ADDITIONAL EVALUATION | ANA | RF | C3 | C4 | HBsAg | Anti-HCV | SPEP | UPEP | RENAL U/S | OTHER

FAMILY HISTORY | KIDNEY DISEASE NO YES IF YES, HOW RELATED | OTHER CONDITION(S) AND HOW RELATED

CURRENT MEDICATIONS *(or attach list)*

KNOWLEDGE

DOES THE PATIENT KNOW HE/SHE HAS KIDNEY DISEASE? YES NO DON'T KNOW

DOES THE PATIENT KNOW THE SEVERITY? YES NO DON'T KNOW

IS THE PATIENT AWARE THAT HE/SHE MAY NEED DIALYSIS? YES NO DON'T KNOW

ADDITIONAL INFORMATION

REFERRED BY | DATE

CONTACT TELEPHONE | EMAIL

For more information about why these data are important to share with the nephrologist, visit www.nkdep.nih.gov.

NKDEP National Kidney Disease Education Program

NKDEP
National Kidney Disease Education Program

Questions or Comments

anarva@verizon.net