

*Keep the Options Open!*

## Key Issues for People on Dialysis & Their Loved Ones: Proposed ESRD Bundle Highlights

### Medicare Bundling Rule

It's here! You may recall from our Q&A (<http://www.homedialysis.org/resources/tom/200907/>) that we've been waiting for Medicare to release a *Notice of Proposed Rulemaking*. Now they have, and it tells us what they plan to put in a new "bundled" payment for dialysis treatments.

**The clock has started on the public comment period.** The deadline is **Monday, November 16<sup>th</sup> at 5:00 pm EST**. Medicare needs to hear from YOU. You don't need to be a policy expert or know the ins & outs of each rule (most professionals don't!). Just share your story and explain how the rules would change your life—for better or worse.



In this guide, you'll find:

- A summary of key points
- How we think they may affect you
- What you can do
- How to submit your comments

### What's *Good* for People on Dialysis?

1. **In the rule, Medicare (CMS) supports home treatment options. There are mentions of PD, nocturnal HD and "daily home HD with compact, portable machines."**

**Why is this good?** No one option will suit everyone all the time. Keeping ALL of the options open means you have more choices now and in the future.

**What can I do?** Help ensure that this support stays in the final rule! Tell *your* story about why you do (or might want to do) home treatment. Thank CMS for their support for making ALL of the options available.

2. **CMS could have paid for dialysis by the treatment, week, or even month. They chose *per-treatment payment*.**

**Why is this good?** Paying by the week or month could have made it hard for you to travel. Deciding how to split up a week's or month's worth of treatments would have been a major challenge for clinics. And, a weekly or monthly bundle might have made more frequent treatments less likely.

**What can I do?** We believe that per-treatment payment is the best way to support more frequent HD. If you agree, include this in your comment.



**3. Clinics can bill for more than 3 HD treatments per week—if a doctor writes a letter saying that extra treatments are medically justified.**

**Why is this good?** CMS is letting your *doctor* decide how much dialysis you need. Taking down some of the barriers can help more people to do frequent HD. (NOTE: Eliminating the need for a doctor’s letter would be even better.)

**What can I do?** If you do more than 3 HD treatments per week, explain *why* and in what ways you feel better. If more frequent HD allows you to work and have a health plan, or give back to the community in some way, this is a good point to make. (NOTE: The Medicare ESRD Program was passed in 1972 so people who needed dialysis could be productive, tax-paying citizens).

**4. CMS is seeking input on quality measures just for home dialysis. (This will be part of a *separate* rule that will go into effect in 2012).**

**Why is this good?** Having new quality measures will help give CMS a chance to see the real value of home treatment.

**What can I do?** Explain how your life has changed due to home dialysis. Have you spent less time in the hospital? How has your blood pressure been? Outcomes like these can be turned into quality measures that CMS can use. Be sure to ask that measures *not* punish clinics that offer home treatments.

**5. IV drugs (like iron, Vitamin D drugs, and EPO) are part of the bundle. This means these drugs *may* be able to be used at home, not just at the clinic.**

**Why is this good?** Having to go to the dialysis clinic to get a lengthy IV drug infusion is a hassle. With the payment barrier gone, drugs *that are labeled for home use* can be given at home.

**What can I do?** If you would prefer to be able to give yourself IV drugs at home, include this in your comment (and say why).



## What's *Bad* for People on Dialysis?

### 1. Home training costs are part of the bundle—not separate.

**Why is this bad?** For years, payment for home training has not even come *close* to matching the costs—it was just \$20/day for one-on-one nursing care (\$2.50/hr!). Home HD training can take 2-6 weeks or so, depending on the machine, how fast you learn, and how much you knew before. If clinics are not paid a training fee that will cover their costs, *it could reduce future access to home HD.*

**What can I do?** *This is the single biggest threat to home HD in the proposed rule:*

- Urge CMS to pay for training *outside* of the bundle or in some way that protects access to training at any time.
- Share *your* experience of training—how long were you on dialysis before home HD? How long did training take? What sort of support did you get (or need) once you were home?
- Help make the case that training is not an *everyday* cost, it's special and needs *separate* payment. (Fewer than 1% of U.S. patients do HD at home—and more should have the chance.)



### 2. You may pay more out-of-pocket for lab tests and oral meds.

**Why is this bad?** Medicare *thinks* this will add \$9/treatment for lab tests and \$14 for drugs—a total of \$23. (It could be more). You would pay 20% (by yourself or with a health plan). This is an extra **\$4.60** per treatment—**\$717.60** per year at three treatments per week (or for those on PD). At five treatments per week, it would be **\$1,196** per year. And at six treatments per week, **\$1,435.20** per year.

**What can I do?** Share your concerns. Are you not able to get a Medigap or other policy to pick up co-pays? How much of a hardship will it be if you have to pay more each month? What will you have to do without? Make this as real as you can so CMS can see the impact it would have on your life and your health.

### 3. Some Medicare Part D drugs used just for dialysis (phosphate binders, Vitamin D drugs, & Sensipar®) are part of the bundle.

**Why is this a concern?** More costly drugs, like Sensipar®, Renagel®, and Renvela® may be hard to get, if doctors stop prescribing them because clinics don't want to pay. And adding these drugs into the bundle turns people on dialysis into *second class citizens*. Why? Because others can get them through Medicare Part D—with extra help to pay, if need be. But on dialysis, you can *only* get them through a clinic, and must pay 20% *per treatment*—whether or not you even need or take these drugs.

**What can I do?** If you think you should have access to these drugs like anyone else on Medicare does—not just through your clinic—include this in your comment.

## Other Issues to Consider

- 4. The bundled rate will be different for each person. “Adjusters” like age and health history can mean that your clinic will make more (or less) money for your care.**

**Why is this a concern?** The new rule is *highly* complex. Clinic staff will have to figure out each person’s payment rate each month—and may have less time to spend on patient care. And, if the rate for *your* treatment is higher, ***so is your co-pay.***

**What can I do?** Suggest a simpler plan with fewer adjusters and a higher base pay rate. Clinics won’t have to spend as much time doing math, and the rates won’t vary as much from person to person.

- 5. The proposed rule would pay more (47.3% more) for your first 4 months of treatment—if you have Medicare. (More than half of people have Medicare when they start dialysis).**

**Why is this a concern?** It *does* cost more to give people a good start. And, the death rate on dialysis is *twice as high in the first 3 months* as it is later. Many who choose PD may start training in the first 4 months. But some may not, and their training would not be paid for. And most who do home HD start *after* the first 4 months. So, clinics would get NO extra payment for home HD training. This could mean fewer clinics will offer it.

**What can I do?** Perhaps some of this first-4-months payment could be used to support home training instead? If you think this would be a good idea, include it in your comments.

- 6. Method II is as good as gone. Suppliers would have to bill clinics for supplies.**

**Why is this a concern?** If you are one of the dwindling number of people who use Method II for home dialysis supplies, this will no longer be a choice for you. And, those who are getting staff-assisted home PD through Medicare (this is not often done) would no longer be able to.

**What can I do?** If the loss of Method II affects you, explain how and why, and what you will have to do instead.

## How to Submit Your Comments

### 1. Online:

<http://www.regulations.gov/search/Regs/home.html#submitComment?R=0900006480a30c15>. You can type in your comments, cut and paste them from a Word document, or upload a file.

### 2. By regular mail:

Centers for Medicare & Medicaid Services  
Department of Health & Human Services  
Attention: CMS-1418-P  
P.O. Box 8010, Baltimore, MD 21244-8010.  
*Please allow time for mailed comments to arrive before the deadline.*

### 3. By express or overnight mail:

Centers for Medicare & Medicaid Services  
Department of Health & Human Services  
Attention: CMS-1418-P  
Mail Stop C4-26-05  
7500 Security Boulevard  
Baltimore, MD 21244-1850

**See the next page for a sample comment. (Note: Yours can be as long or short as you like—put key points in bold!)**

## **Sample Comment:** *By Erich Ditschman*

***Availability of all dialysis options*** - Thank you CMS for making all dialysis options available in the proposed Medicare Bundle Rule. I am especially grateful for the language that you are using concerning “daily home HD with compact, portable machines.”

Four years ago, when my second kidney transplant failed immediately due to Focal Segmental Glomerulosclerosis (FSGS), I went from peritoneal dialysis (PD) to in-center hemodialysis (HD). On in-center HD three times a week, I had significant trouble controlling phosphorous and potassium, even when dutifully following the renal diet. My energy level was very low and my hematocrit sailed up and down like a Duncan Yo-Yo. Also, I found myself the epitome of the traditional patient. I would use EMLA cream to deaden the stick. I looked away and wanted nothing more than for the whole ordeal to be over. I turned into a *Price is Right* zombie like the five patients to the left of me and the three to right of me, all of us being taken care of and waiting for our time to be done.

My dialysis provider only offered traditional machine home HD. Five years earlier after my first kidney transplant failed due to FSGS, I went home on a traditional machine. The amount of time it took my wife to set up the machine, run my treatment and sterilize it afterward was negatively impacting the time my 3-year old son needed from us. It was not very user-friendly to our home environment and I still had all the physical problems mentioned above.

After I returned to traditional dialysis, I read in an issue of *Nephrology News and Issues* an article about the NxStage System One. I am the father of two children, Jacob who is now 10 years old and Antonia who is 5 years old.

I want to note that my wife and I adopted our daughter while I was on PD during the time between my two kidney transplants. We would not have been able to adopt our “Nia” had I been on in-center HD, since my wife needed to work full-time and I would not have had the energy or time to be a full-time father. I am particularly proud that we were able to expand our family while on dialysis.

Our family has always enjoyed traveling, and it was easy to do when I was on PD. The System One seemed to be the ideal dialysis machine to enable me to be a better father and to get my family traveling again.

I had to switch providers to get trained on the System One. Thankfully, my nephrologist who had always been associated with my first provider and traditional in-center HD, was amenable to being re-credentialed with the new provider who offered “daily home HD with compact, portable machines.” My major hurdle was self-cannulation. I knew however, that I would have to overcome this fear in order to get home. What I found is that once I did self-stick, I no longer felt like I was the epitome of a dialysis patient. I felt liberated and in charge of my life. Being home on daily HD has only strengthened that feeling.

A year ago, I once again switched providers and my nephrologist again got re-credentialed so that I could switch to extended home HD while I slept at night. With research now indicating that slower, longer, more frequent dialysis may provide the same outcomes as a cadaveric kidney, I

now have renewed hope that I will see my Antonia graduate and even one day far from now, hold a grandchild.

Now, my potassium and phosphorous are never a problem and my energy level is the best that it has been since losing my kidneys. Perhaps most importantly, I have a sustained libido which seemed to have been lost until I found frequent home HD. Also, freeing up the 3 hours a day that I had to spend doing short daily home HD has given me time to be very active in my community. I am a Den Leader of my son's Webelos Cub Scout Den. I am the volunteer leader of a *Safe Routes to School* initiative at my children's school. I am on the Board of Directors of *Dialysis Patient Citizens* and have raised over \$50,000 dollars for the *National Kidney Foundation of Michigan*. Our life, while as chaotic as most families of young children, is very stable, productive and happy - all because I am able to undertake home HD with a small portable machine.

***Per-treatment payment*** - Because I now dialyze three days on and one day off, I believe CMS's choice of per-treatment payment is appropriate. It is vital to my well-being and that of my family that I get the number of treatments necessary to keep me healthy and ensure my longevity. Likewise, it is vital that CMS retain per-treatment payment as described in the Rule.

***Medically justified extra treatments*** – While I may not have the strength and stability to go back to work, I have been the primary care giver to my young children, Jacob and Antonia, while my wife works full-time. Because I get six treatments in an 8-day stretch, I have been able to be very active in my community. In addition to the activities mentioned above, I have sat on the *City of East Lansing Environmental Commission* and

am working on my church's landscape committee. I do all of the grocery shopping and prepare nutritious, tasty meals for my family. I regularly donate jewelry that I make to community auctions and organize a team that participates in the National Kidney Foundation's local walk, that on average raises \$5,000 a year. I would not be able to keep this pace if I were to be restricted to three times a week dialysis. Furthermore, **I have not been hospitalized since I started home HD with a compact portable machine.** More frequent medically justified treatments keep me safe and healthy.

***Quality measures for home dialysis*** – It is important that CMS identify quality measures just for home dialysis. In addition to my quality of life flourishing on more frequent extended duration home HD, I have had very stable blood pressure. My blood pressure is regularly 115/76 +/- 5 and I only take a small dose of Coreg to maintain my pulse. While on three times a week traditional in-center HD, I was regularly in the 140's/90's and on two to three blood pressure medications to maintain that. I once contracted a Staph infection while on traditional in-center HD, which required heavy dosing of antibiotics to treat. Since being on home HD I have been infection free.

I'm not sure how to measure this quality, but while on in-center HD, I have had fellow patients die next to me. Additionally, being seated for hours next to older and sicker patients and amputated patients has a psychological toll on one's spirit. Rather than lifting one up and making one feel good about their condition, such surroundings drags one down, making them feel more like a victim of their disease. In the company of one's loved ones at home the feeling of being a victim vanishes. Instead of feeling like a patient, at

home you can once again be an involved and active family member sharing hopes and dreams with your children and wife. CMS should seek input on both physical, social and psychological, quality measures.

***IV drugs as part of the bundle*** – I administer my Epopen twice a week at home. I currently have to go to an infusion center for weekly Venefer injections. While at the infusion center I often have to get stuck four times before a proper connection can be made. Not only is this a time inconvenience, it hurts. I would prefer to give IV drugs at home during treatment as I do with Epopen. If including IV drugs in the bundle will help to make it possible for me to administer them at home then I am very supportive of this measure.

***Home training costs*** – My training took 3 weeks of approximately 5 hour days in a one-on-one situation with an RN and a technician. It also required me to drive an hour each way, because no one in the Lansing area was offering short term daily home HD.

I am concerned that if training costs are incorporated in the bundle, there will be no incentive for providers to invest in the upfront cost of training, especially since the payback period may be 1-2 years. When I switched from short term daily to extended nocturnal daily HD, I trained for *another* week. In both cases, I was self-sufficient once home because of the intensive individual attention that I received from my providers. This, however, may not be the case for all patients who wish to come home. Some who are unfamiliar with machinery or are apprehensive of undertaking their own medical care may need more time. Home training costs should be reimbursed at a rate that reflects the true cost of providing training.

Reimbursement should be flexible to allow for a reasonable amount of training for the average patient. It should also be available *anytime* while a patient is on dialysis. I have done all dialysis options at one point in my nearly 10 years on dialysis and I needed to be trained for each one, save in center dialysis. It is important that training be reimbursed adequately and when needed by the patient. In general, the initial modality a patient chooses may not always be in the best interest of promoting the best outcomes and quality of life for that patient.

Inadequate reimbursement for training should not limit the availability of home HD for those who want it or for those whose physicians think it will offer the best outcomes. Training costs must be adequately reimbursed, if not then it may not be in the provider's interest to make it available. I can't imagine my world without home HD. It is unfathomable to think that the US would not take full advantage of a technology that allows its citizens to live productive, long and well lived lives and would not do everything that it can to provide access to it.

In closing, I would once again like thank CMS for including all dialysis options available in the Medical Bundle Rule. Home HD with a small portable machine has given me much of a life back that I once thought was gone forever. I may not have the energy that I did prior to losing the use of my kidneys, but home HD delivered frequently and for a long and slow duration has provided a level of normalcy to our family that has allowed us to grow as a happy and productive family and a vital part of our community.

