

## U.S. Dialysis - How the System of Care Works

### Who Offers Dialysis

Dialysis in the U.S.—both home dialysis and in-center care—is provided through clinics that are certified by Medicare or the Veteran's Administration. Also called "units," "centers," or "facilities," dialysis clinics must follow a set of Medicare regulations called the *Conditions for Coverage* that were first released in 1976, with a proposed update released for public comment in 2005.

Each clinic is required to have the following staff, called the "care team" to provide care to home and in-center dialysis patients:

- A medical director
- Registered nurses (at least one present on each shift)
- A renal dietitian
- A social worker with a master's degree

Clinics in every state except Montana also have dialysis technicians, who provide direct care to in-center patients. Techs are required to have formal (book) training plus on-the-job supervision before they can provide care by themselves. After the training, each nurse may supervise three or more techs on each shift, and each tech may care for four or more patients at a time. Five states (Arizona, California, Ohio, Oregon, and Texas) require techs to be certified and pass an exam. Seven other states and the District of Columbia have laws that require certain training for techs (Connecticut, Kentucky, New Mexico, South Dakota, Virginia, Washington, and Utah).

There are more than 4,400 Medicare-certified dialysis clinics in the U.S., and they are organized much like restaurants. About a third are either independent (think "mom and pop diner") or small clusters of clinics with a single owner, often a doctor. A few clinics are still hospital-based, but most are free-standing. About two thirds of clinics are owned by *large dialysis organizations* or LDOs (corporate "chains," like McDonald's). The largest LDOs in the U.S. right now are:

- DaVita - 1,200 clinics after its merger with Gambro
- Fresenius Medical Care (FMC) - 1,000 clinics
- Renal Care Group (RCG) - 415 clinics
- Dialysis Clinics Incorporated (DCI) - the largest non-profit chain, with 150 clinics

Depending on where you live, there may be only one clinic, or you may have many to choose from. You can find out your dialysis clinic options on Medicare's website at:

<http://www.medicare.gov/Dialysis/Home.asp>. On this site, you can:

- Search for a clinic in the U.S.
- Learn how each one compares to others on key quality measures
- Download helpful checklists to take with you when you visit clinics or talk to clinic staff

If you're looking for clinics that offer any of the types of home dialysis, visit our "Find a Center" database right here on Home Dialysis Central ([www.homedialysis.org](http://www.homedialysis.org)).

## How Dialysis Quality is Maintained

The most important thing for you to know about dialysis clinics is that they can differ—a *lot*. Most people choose a clinic based on where their doctor sends them, how close it is to home, or how easy it is to get to. But some clinics offer much higher quality care than others, and some clinics offer only one form of treatment—while others offer several types of dialysis so you have more options. You have a right to choose your doctor and your clinic (within the limits of what your insurance will pay for).

Getting good quality care is the most important way that you can have the best life possible on dialysis. There are a number of different ways that quality is monitored and improved in dialysis:

- State surveyors inspect each dialysis clinic to ensure that they follow the Medicare regulations. Inspections can be done at any time if there is a complaint. If no complaints are made, clinics get surprise inspections as time is available. A U.S. General Accounting Office (GAO) study released in October, 2003 found that, while states are expected to survey all clinics within three years, only nine states met this goal. Five percent of clinics had not been inspected in nine years.
- Large dialysis organizations track the care given in their own clinics, and do *continuous quality improvement* (CQI) projects to help all of their clinics improve their patient outcomes. Independent clinics may also do CQI projects to improve care. Medicare Surveyors may ask clinics about their CQI programs when they do an inspection.
- The End-stage Renal Disease (ESRD) Networks, a set of 17 regional, non-profit dialysis oversight agencies, collect data, oversee quality, and handle patient grievances. They track a set of "Clinical Performance Measures" (CPMs) of dialysis quality and report on these in the USRDS Annual Data Report. Networks also provide some patient education and encourage rehabilitation and do CQI projects. You can find your Network at [www.esrdnetworks.org](http://www.esrdnetworks.org).
- Kidney Disease Outcomes and Quality Indicators (K/DOQI) Clinical Practice Guidelines put out by the National Kidney Foundation address a number of areas of care. Based on a thorough review of medical research and the opinions of a national panel of experts, these guidelines form the basis for measuring the quality of dialysis medical care. *The guidelines are a minimum*. Care that meets—or *exceeds*—K/DOQI Guidelines is what you'll need to be looking for.
- National statistics on kidney failure, including patient age, gender, and race; treatment type; cause of kidney disease; measures of quality; and much more, are collected each year and compiled into a resource called the *United States Renal Data System* (USRDS) Annual Report. These statistics are used to look at national and regional trends and assess whether dialysis care is getting better across the country. You can download the USRDS report at <http://www.usrds.org/adr.htm>.

## How Dialysis is Paid For

Something important happened in the early 1970s that allowed dialysis to go from an experimental option in short supply to a life-saving treatment offered to nearly anyone who needs it: Medicare coverage. Passed in 1972 after passionate testimony to Congress from patients and doctors, the Medicare ESRD Program remains the only single-disease Medicare program to this day. The program covers Americans of *any* age who need dialysis or a kidney transplant to treat kidney failure—if they have worked enough to qualify for Social Security benefits (93% of Americans qualify).

Medicare kicks in at different times, depending on which type of dialysis you choose. If you train for home dialysis, Medicare begins right away. If you do in-center hemodialysis, Medicare won't start until the first day of the third full month after treatment starts—and you are responsible for any charges that occur before then. This was done on purpose by Medicare to encourage people to do home dialysis.

Once Medicare does start to pay, it will be the **primary** insurer if you have no group health insurance through an employer. In this case, it will pay 80% of the "usual and customary" fee for dialysis—and you will need to pay the rest. The balance can be paid by Medicaid (if you qualify for it), Medigap, or a private health insurance policy. Some states also have aid programs. Once you start dialysis, the social worker or financial services assistant at the clinic can help you figure out your options.

Clinics bill Medicare directly for dialysis services. The amount the clinic is paid is called the *composite rate*, a fee of around \$130 per treatment for clinic overhead, staff time, supplies, and drugs you receive during treatment. The clinic receives only 80% of this rate, or about \$115. This figure was \$138 in 1974, and is worth less than \$34 today in real dollars. In fact, clinics *lose* \$5-10 on each in-center dialysis treatment for patients who have Medicare and no other insurance.

Unlike hospital and nursing home fees, the composite rate is *not* automatically increased as the cost-of-living goes up. Instead, Congress must pass a law to raise this rate. This has only happened three times since 1983 (the composite rate was reduced once, in 1986, as well). An alliance of kidney organizations and companies called Kidney Care Partners (<http://www.kidneycarepartners.org>) is working to change this. (The Medical Education Institute (<http://www.medicaleducationinstitute.org>) which created Home Dialysis Central is a member of Kidney Care Partners.)

If you *do* have—and keep—an employer group health plan when you start dialysis, that plan will be **primary** for your first 30 months of treatment, and Medicare will be **secondary**. This is important for two reasons:

- When you have a primary *and* a secondary insurance plan, you're likely to pay less out of pocket. Charges that are not paid by one plan may be covered by the other.
- Clinics charge private insurance companies something closer to the true cost of care. This extra income is what keeps the whole dialysis system afloat.

It would be easy to write an entire book about paying for dialysis—and, in fact, Life Options has done just that in a booklet called *A Kidney Patient's Guide to Working and Paying for Treatment*. To learn more, you can download this free booklet from the Life Options website, at [www.lifeoptions.org](http://www.lifeoptions.org).

### **Who Provides Products and Services**

A variety of private and publicly-held companies—too many to list here—produce the medications, needles, tubing, artificial dialyzers, dialysis fluids, dialysis machines, water treatment equipment, and other products used in dialysis. These companies, or vendors, can be important to you because they are often sources for patient information. A number of them are sponsors of Home Dialysis Central, and you can learn more about them by clicking on their logos on our home page.

In general, look for information about a health problem (e.g., blood pressure) rather than a particular product (e.g., a certain drug). Health information may be more likely to be unbiased, accurate, and complete than product information because it is not trying to sell you something. Product-specific information may be most helpful when it alerts you to symptoms or side effects to watch out for.

For a complete list of vendors who offer products and services to help treat kidney disease, look to the January "buyer's guide" issue of the trade magazine *Nephrology News & Issues* (<http://www.nephronline.com>). U.S. patients with kidney disease can subscribe for half price, or \$27.50/year, by calling (800) 719-9682. Many dialysis clinics also receive at least one copy of *Nephrology News & Issues*.

### **Voluntary Kidney Organizations**

Support and information are key to living well with kidney disease, and an array of organizations offer both, including:

- The **Life Options** program is dedicated to helping people live long and live well with kidney disease, with a wealth of free info for patients and professionals: <http://www.lifeoptions.org>
- **Dialysis\_Support** is an email support listserv with more than 750 members at all stages of kidney disease who help and support each other: [http://health.groups.yahoo.com/group/dialysis\\_support/](http://health.groups.yahoo.com/group/dialysis_support/)
- The **Renal Support Network** helps link kidney patients together through "Bridge" groups for education, support, and advocacy: <http://www.renalnetwork.org>
- Join a patient council of the **National Kidney Foundation**: <http://www.kidney.org>
- The **American Association of Kidney Patients** is a membership organization with a magazine, free materials, and an annual patient meeting: <http://www.aakp.org>
- The **Kidney Transplant/Dialysis Association** (KT/DA) provides financial aid, information, and emotional support to kidney patients and families: <http://users.rcn.com/ktda1/index.shtml>
- The **Oxalosis and Hyperoxaluria Foundation** (OHF) is a gateway to information about these kidney-stone producing conditions. Learn all about it at <http://www.ohf.org/index.html>
- The **American Kidney Fund** offers direct financial help to patients, and much more: <http://www.akfinc.org>