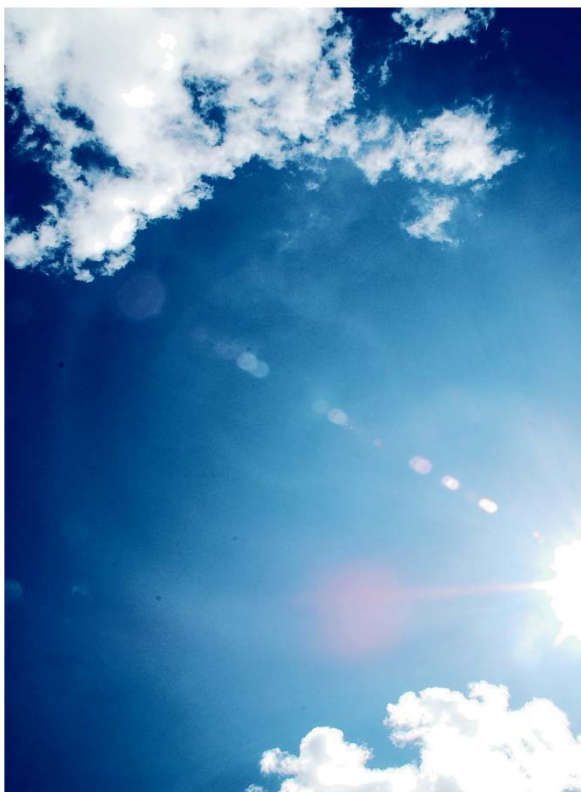


Dialysis and Your (Health-related) Quality of Life

Dialysis *saves* your life, but it can also *change* it. Depending on which type you choose, dialysis may change what you can eat and drink, how many meds you need, and what you can do each day. If you work, dialysis can make you more or less able to keep your job. **Health-related quality of life (HRQOL)** is *your* rating of:

- Your own physical health
- Your own mental health
- How much of a burden kidney disease is

As it turns out, HRQOL is vital. Why? Because *it predicts your risk of a hospital stay and a longer or shorter life*. And there are steps you can take to improve your HRQOL and your chances of living long and well.



Taking the KDQOL-36 Survey

Your social worker will measure HRQOL by asking you to take a survey called the **KDQOL-36**, which has 36 questions in 5 sections:

- Physical health
- Mental health
- Burden of kidney disease
- Symptoms and problems
- Effects of kidney disease on daily life

The questions ask things like, “During the past 4 weeks, how much were you bothered by itchy skin?” or, “Too much of my time is spent dealing with my kidney disease” (True/False).

There are no right or wrong answers. The point is just to find out how you feel about your own life in each of the five areas. The survey takes about 10-15 minutes to do. Not sure what to answer? Go with your first instinct. It’s best if you can complete the survey by yourself. The social worker may help you if you can’t—but answer honestly. The scores won’t mean a thing if you pretend to feel better than you really do.

You can choose not to take the KDQOL-36, or not to answer a question. *Please answer the first 12 questions, though!* Your clinic needs at least those 12 to look at your risk of poor outcomes and offer you help if you need it.

Medicare Requires HRQOL Surveys

New Medicare rules as of October 14, 2008, require clinics to give all adults on dialysis

the KDQOL-36 at least once a year. The results must be used to help make a Plan of Care for you, to help you feel your best. KDQOL-36 results are also a “benchmark” of good dialysis care across the U.S. So, like blood tests, results will be sent (as a group) to Medicare. They will help find out how people on dialysis in the U.S. feel physically and mentally and what helps them do better.

Having Medicare require the KDQOL-36 is a *big deal!* It marks the first time that clinics must ask *you* how you feel instead of just checking your blood tests.

A Life-and-Death Matter

The link between low HRQOL scores and the risk of hospital stays and death was first found more than 10 years ago. A doctor gave a HRQOL survey to 1,000 people on dialysis. Two years later, those who rated their physical function low were more likely to have had a hospital stay. And, they were twice as likely to have died.ⁱ

Other studies have found the same thing. In more than 14,000 people on dialysis, each 1 point higher in physical function dropped the risk of death or a hospital stay by 2%.ⁱⁱ Mental function was a predictor, too. A study of 10,030 people all over the world found that those whose scores were in the bottom 20% had a 56% higher risk of

hospital stay and a 93% higher risk of death.ⁱⁱⁱ

In fact, HRQOL scores are as good as serum albumin (protein) levels or dialysis adequacy at predicting how well you will do.

How to Improve YOUR Odds

When you take the KDQOL-36 survey, your clinic should give you your scores. If they don't, ask for them! Knowing how you did compared to people who are like you in age, gender, and diabetes will tell you a lot about your own future risk.

Using the KDQOL-36 to measure HRQOL scores gives you and your clinic vital information that can't be found in any other way. Your social worker will talk with you about your scores. He or she may ask you what *you* would like to focus on if your scores are not all where you would like them to be. If not, tell him or her what you want to work on. Studies have found a number of things that can help improve HRQOL scores. Some of them might work for you:

- **Set goals.** Knowing where you want your life to go and taking steps to get there can help you feel better. A study found higher HRQOL scores among people who learned how to set goals.^{iv}



- **Exercise!** Many studies have found that exercise helps fight depression and improves physical function.^{v,vi,vii,viii,ix} Out of shape? Talk to your doctor first, start slow, and build up. You don't have to do jumping jacks. *Anything* that gets you moving—from walking with a friend to gardening or mowing the lawn to ballroom dancing—can help.
- **Use a cyclor for peritoneal dialysis (PD).** People who used a cyclor scored higher than those who did their PD exchanges by hand^x (perhaps because doing PD at night allowed a fuller life). After 13 weeks, those who used icodextrin PD fluid had higher scores, too.^{xi} If you use icodextrin, talk with your doctor or home training nurse to be sure the blood glucose meter you use will read your blood sugar right.
- **Get more hemodialysis (HD).** Short

daily HD is done 5-7 days/week for 2-3 hours at a time. Nocturnal HD is done while you sleep, 3-6 nights/week for 8 hours or so. *Either one improves HRQOL scores.*^{xii,xiii} This may be in part because those who use these treatments have fewer cramps, headaches, blood pressure drops, and other symptoms and it takes less time for them to feel normal after dialysis. People who get more treatment feel better.



- **Treat anemia.** Feeling tired, cold, and weak due to anemia (a low red blood cell count) can mean you don't have the energy to do things you need and want to do. This can reduce mental and physical function scores. Treating anemia helps improve HRQOL.^{xiv,xv}
- **Treat bone disease.** Renal bone disease can cause pain and fractures. In a study, some people used the drug cinacalcet to reduce levels of parathyroid hormone and keep their bones healthier. They had higher HRQOL scores than the control group, which was given a placebo.^{xvi}
- **Treat restless legs syndrome (RLS).** RLS causes a “creepy-crawly” feeling in the legs that makes people *have* to move.

It interferes with sleep, and good sleep is needed for you to feel your best. Using a drug called gabapentin eased RLS symptoms, aided sleep, and improved HRQOL scores.^{xvii}

- **Treat carnitine deficiency.** Carnitine helps your body burn fat for energy. It is found in nearly every cell. Dialysis can use up stores of carnitine, and add to fatigue and heart damage. In a study, people who were given carnitine for 24 weeks had much higher HRQOL scores than those who were given a placebo.^{xviii}

Talk to your doctor. Medicare pays for the drug in some cases.^{xix}

Conclusion

Your HRQOL scores on the KDQOL-36 survey are vital clues about how well you are doing now, and may do in the future. Anything that makes you feel better physically and/or mentally can help you to stay out of the hospital and live longer. So, set a goal. Take a step! Let your dialysis team help you reach your goal. Move forward toward a good life on dialysis.

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