



# Your Life – Your Choice

Learn how you can have the best possible life

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There is a topic I am most passionate about – *It is how to improve our quality of life.*

My goal in this article is to challenge you/ to encourage you to take control of your life - to help you make healthy choices about your treatment and how you live your life. So here goes.

Recently I read a report about two research studies. Between the two studies there were a total of about 6,500 dialysis patients who were split into 3 different groups:

**1<sup>st</sup> group** - Patients who made self-directed, choices of modality, i.e. in-center, frequent home hemodialysis, or peritoneal dialysis. Those decisions were based on information they had received;

**2<sup>nd</sup> group** – Patients who worked with their care team to decide;

**3<sup>rd</sup> group** - Patients who allowed their care team to choose for them.

Five years later, the patients who made their own choice (Group 1) were significantly more likely to live longer, healthier, happy lives and to get a transplant. This was true even after ruling out other factors such as age, sex, race, other illness, blood test levels, level of kidney function, education, work, and marital status.

**Let me repeat!** When self-directed with information, patients who make their own choices live longer, healthier, and happier lives. **This is not JUST some interesting information.** These studies show how important *your* involvement in your treatment is, as well as in the length and quality of your life.

This means that **you can make** choices and that **the**



# Choice!

## able life on dialysis

**choices you make** will have a **powerful impact** on your quality and length of life.

One important choice you need to make is on how **you** are going to receive your dialysis.

I have had the opportunity to give talks to dialysis professionals about the topic of patient empowerment on a number of occasions. At the beginning of each talk, I ask the same question, “If you were, health wise, able to choose any modality (in-center hemodialysis, home frequent hemodialysis or peritoneal dialysis), how many of you would choose in-center dialysis?” The answer is always the same. In a group of 4 to 500 professionals (I mean doctors, nurses, dietitians, social worker, techs, etc.) I will have only 1 or 2 who raise their hand and say that they would choose in-center treatment.

So, what do the professionals know that leads them to that choice? I am a dialysis social worker of over 18 years and I know why I would choose home treatment.

### Let me count some of the whys.

1. I like the idea that I would be in control of when I would do my treatment.
2. Since I would not be locked into in-center treatment days and times, such as (i.e. MWF at 11 a.m., I would be far more able to travel, to choose when I will do my treatment.
3. I would schedule my treatment *around my life* – not *my life around my treatment schedule*.
4. Home patients report feeling stronger, being able to work again and/or do more around the house.
5. Home patients report less restless leg syndrome.
6. They sleep better.
7. They have far fewer and shorter hospital stays.
8. Most patients need fewer medications.
9. There are less diet restrictions.
10. Less stress and higher reported quality of life.
11. **Again**, they report a higher quality of life.

The life we experience is largely based on the decisions we make or don't make. The decisions that we postpone making are still decisions. Think about the decisions you have been making and what decisions you can change to new choices.

The goal of this article is to challenge you to become informed, empowered and responsible for your treatment. **You** are the patient. **You** have the right and **obligation** to ask your doctor questions. **You** have the right to do research and talk with your treatment team. This is **your** body/your life. **You** will live with the consequences of **your** choices or **non**-choices.

What are some first steps you can take to making active decisions in your life?

Starting today you can:

### Set goals – What quality of life do you want?

Gather evidence and know your options and then begin to make the healthy choices that will help you achieve your goals. You might start by looking into the benefit of home dialysis for you. You are the patient, you have the right to explore your options and if your doctor will not assist you, you have the right to change doctors. However, also remember that as we ask the hard questions, we do this with respect. A gentle word is heard much clearer than an angry shout.