



**HOME DIALYSIS** CENTRAL

A program of the non-profit 

# Dialyze to Live

Real stories about *living* on home dialysis

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# INTRODUCTION

When you find out that you will need dialysis to live, it is normal to feel overwhelmed. It's hard to make a treatment choice when what you want is for this to not be happening to you. Please don't panic. The people in this booklet all want you to know that **there is life after starting dialysis**. Change is a constant in life. Your new life will not be exactly what it was—but it can be a good life, just the same. When you choose a treatment that is a good fit for you, and you manage your care, you can embrace life the way the vibrant people in these pages have done!

Most people know that dialysis can be done in a clinic three times a week. But, far too many are never told that you can have a better, fuller life if you learn how to do your treatments at home. In the next few pages, you can learn a little about each of the types of home treatments. Here is a chance for you to hear from people who live well on home dialysis. Some people do the same type of treatment for 10 years or more. Others switch between types of treatments, or get one or more kidney transplants. As your life changes, so can and should your treatment.

The people we talked to for this project are your friends, relatives, and neighbors. The only difference is that they use some form of home dialysis to live. Read on to see their "new normal".

## KIDNEY DISEASE FACTS

- One in seven Americans are at risk for chronic kidney disease (CKD).
- 26 million Americans have CKD.
- 590,000 Americans have kidney failure.
- 400,000 Americans are now on dialysis.
- 100,000 Americans are waiting for kidney transplants.
- Only 16,000 Americans received transplants last year.

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## KENNY MOSES JOHNSON

### PERITONEAL DIALYSIS

At 19, I learned that my kidneys would fail due to IGA nephropathy. I never let the disease stop me from living life to the fullest.

I'm a steamfitter in UA Local 38 Plumbers and Steamfitters Union in San Francisco. One day in 2006, I was struck by a large pipe and fell down a shaft. I had a brain injury—and 3 weeks later a car accident caused a second head trauma. I was very depressed during my recovery. With a head injury, I couldn't judge when I would get better. I take pride in my work as one of the best steam fitters in San Francisco!

*"I know nothing in life is perfect. But I believe a positive outlook will determine my outcome. It's not your position in life but your attitude."*

Once I did, I went back to doing what I loved since I was a kid—motocross racing! In 2007, I joined the Over The Hill Gang motocross racing club. I won two back-to-back championships. In the winter of 2013, nearly 30 years after my doctor first told me about my kidney disease, I had to start dialysis. I learned about my options. And, I chose peritoneal dialysis (PD) so I could keep my job and keep racing. The PD tubes were a lot like my steam fitting pipes, so it was easy to learn. I carry my PD supplies with me wherever I go, and "keep it clean" is my motto.



In 2013 I had a heart attack and needed a triple heart bypass. I know nothing in life is perfect. But I believe a positive outlook will determine my outcome. It's not your position in life but your attitude. And, my fiancée, who is my perfect life match, is also a perfect match for my kidney transplant this summer. I truly believe that your attitude will determine your fate.

## ZOLA COATES PERITONEAL DIALYSIS

In 2009, I had a stroke. I didn't know this at the time, but it caused some damage to my kidneys. This was not found until 2012, since my slide into "kidney brain" was so slow that I never noticed. As it turned out, my type of kidney disease comes from diabetes. My dad, sister, and brother all had diabetes and sadly, they have all passed. It bothers me that in all the years of my family being treated for diabetes, no one ever told us that our kidneys could be affected.

*"This is your new life, no matter how you look at it.  
It's just something you have to get used to."*

I had a girlfriend who was on peritoneal dialysis (PD), so I knew how it worked. Once I had to start dialysis, I knew I wanted to do PD. After using a chest catheter for hemodialysis for my first few months, I started PD at home with the cyclor. This is your new life, no matter how you look at it. It's just something you have to get used to. Most important, you have to change your lifestyle.

So, I did. I work part-time for a small company, and spend time with my three grandchildren—two girls and a boy. I love to play Spades on the Internet, and, just, in general, enjoy life. Attitude is everything! I am on the transplant list, and until then, life goes on. I am very strong, and, with God's help, He keeps me going every day, and I am glad about that!



## BARRY GONZALEZ

### DAILY HOME HEMODIALYSIS

A few years ago, I was the busy manager of a furniture store and father to three young kids. At work one day, I had a high blood pressure episode. I passed out and awoke in the hospital. While recovering, my doctors told me that my blood pressure was still out of control, and it had done severe damage to my kidneys. I would need to start dialysis to survive. It was a shocking blow.

I had been told before that my blood pressure was too high, and that it could affect my kidneys. But I was young, and felt fine, so I really didn't pay too much attention to the warnings. I didn't realize that I could end up where I was, needing dialysis at just 27 years old. I wish I had taken better care of my health.

I started going to a center three times a week for 3-4 hour treatments. It was a difficult change. After just a few months, I could no longer keep my job at the furniture store and quit, which put a strain on our finances. I felt sick, tired, depressed, and resentful of my kidney disease. I wasn't a "good" patient. I missed treatments and didn't follow the diet limits. Because of this, I was told that I was not able to get on the transplant list.

After a time, I started to come to terms with my condition. I couldn't change the fact that my kidneys had failed. The only thing I could control was how I dealt with the here and now. I needed to be as healthy as I could for my kids. I started taking better care of myself. I began eating better and tried to exercise more.

One day, at the clinic, I learned about home dialysis. I had never considered that I could learn to do my own treatments when and where I wanted. Being independent, I knew I wanted more control over my care. With my wife, who is my trained partner, I completed the training and went home about a year ago.



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## BARRY GONZALEZ

DAILY HOME HEMODIALYSIS *CONTINUED*

Since then, my life has been transformed. I dialyze more often (six times per week) which has significantly improved my health. My blood pressure has dropped. My appetite is back. I sleep much better. I've even begun running almost every day. Instead of leaving for a few hours to get my treatments, I can sit and watch TV with my kids. Dialysis is no longer an intrusion on my life, but a part of it.

*"I don't feel like a "sick person" anymore. I'm proud to tell people that I do my own treatments at home!"*

With my schedule now more flexible, and since I feel so much better, I started a new job in retail. I have enough energy now that you would never know by looking at me that I live with kidney disease. I'm a patient, but I can keep up with anyone else. I don't feel like a "sick person" anymore. I'm proud to tell people that I do my own treatments at home!

When I meet people who have kidney disease, I tell them about home dialysis. I want to share my story with others in the Hispanic community. Diabetes and obesity are more

common in our people, and both are major causes of kidney disease. In fact, about 11% of Hispanic Americans have diabetes. And, of these, about 1/3 don't know it and are not treated. Many Hispanic people may not be aware that they're at risk for kidney failure. I know I wasn't.

For me, doing dialysis at home has helped me take charge of my health and, in many ways, given me a second chance in life.



## LISA CALESTINO

### DAILY HOME HEMODIALYSIS

I started dialysis at the age of 13 due to a kidney problem I was born with. Since then, I've had transplants (of limited success). I've done two types of peritoneal dialysis (PD). And, I've done standard and nocturnal in-center hemodialysis (HD) (2007-2010). For the last 5 years, I've been on short daily home HD. My treatments are 4-5 days per week for three hours each.

*"I love the freedom of short daily HD, which allows me to work as a vet tech, as well as practice massage therapy."*

I love the freedom of short daily HD, which allows me to work as a vet tech, as well as practice massage therapy. My husband is my care partner. Most of the time, I set up the machine before he comes home and put in my own needles. Then, he helps with taking my blood pressures and does the charting. Most days, he hooks me up, but I can too. He pulls out my needles so I can hold both at the same time, which is quicker. He or I take the machine down. My labs are good, and I feel great!

With my trusty machine, we have gone to Seattle, Las Vegas, Niagara Falls, and Michigan. We also took a cruise to Alaska. And, I even flew to Europe a while ago, but set up dialysis in-center while I was there. We just spent a week with family in Florida this spring, too.

Update: Lisa has had a kidney transplant since she wrote this, and we wish her well!



## MARCIA AND DENNY BURGESS

### NOCTURNAL HOME HEMODIALYSIS

I'm Marcia, Denny's wife of 13 years, and his care partner. When we said, "I do", he had already been on dialysis for over 16 years. Denny's health had been compromised since he was 1-1/2 years old. He couldn't play sports, so he picked up the guitar when he was young, taught himself to play, and has been in bands since he was 14 years old. Denny is a man of few words, but a heart full of song!

When Denny and I first met, we both played in different country bands, and also in the same gospel band. After we got married, we had our own band. Having a barn for dances was a lifelong dream Denny had. My folks lived on the farm where my mom grew up, which had a large barn where cows and hay were once kept. Denny and I live about 7 miles away.

*"I don't have to be on dialysis—I get to be on dialysis. If I don't feel well, it's my own fault."*

One Sunday, Denny asked my dad if he would let us have the barn and clean it up for dances, since he was retired from farming. Dad thought about it awhile and said yes, under 3 conditions: 1. No drinking. 2. No smoking. And, 3. He didn't want to have to do a darn thing! Of course, Dad really got into it and helped. So we are in our 10th year of having barn dances on the 3rd Saturday of April thru October. Our band is the house band and we have a special guest each month.

When Denny turned 40, he wanted to have a party, since he never thought he would make it to that age. We had a party in a little bar, and it was packed. Then, we kept it up and it got bigger and bigger. We have been in 4 venues now and have a crowd of around 200 people who show up each year to help Denny celebrate life. We just celebrated 29 years of dialysis last February!



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## MARCIA AND DENNY BURGESS

### NOCTURNAL HOME HEMODIALYSIS *CONTINUED*

Way back at the start, Denny did home dialysis—before there were any centers in Iowa. When centers popped up, he went in-center. Then, 8 years ago, he took part in a study at the University of Iowa of nocturnal dialysis with the “Baby K” machine. The study did not reach its goals, because it didn’t get enough people. But, Denny is now the picture of health! His labs are better than perfect. He takes few, if any, medicines. He has no diet limits. And, even his enlarged heart (from the in-center treatments he did) has gotten smaller. He does have spinal stenosis (not from dialysis), and that ended his career as a truck driver. But it hasn’t kept him off the stage of our very own Lighthouse Opry Barn Dance. Denny got a transplant in 1993, but it failed right away. He never stopped dialysis—or playing music!

Denny does nocturnal dialysis for 5 nights a week, 6-8 hours a night. I set up the machine, and Denny puts in his needles. Then I go relax for a bit, while he settles in. We’ve had no major issues. But, we do have to keep an eye on the weather. We live in the heart of “tornado alley,” and if the warning siren goes off, we quickly unhook.

Denny says, “I don’t *have* to be on dialysis, I *get* to be on dialysis” and, “if I don’t feel well it’s my own fault.” He lives the life he wants to live, and our family, his son Chad, my daughter Krista, and I all love him for it!



## TINA HARRISON

### LOTS OF OPTIONS

I found out that I had FSGS (Focal segmental glomerulosclerosis) at 15, and I have been on some form of dialysis since the age of 25. Over the years (20 to be exact), I've tried it all:

- A transplant
- In center dialysis
- Short daily treatments at home
- Nocturnal hemodialysis (while I sleep)

*"I was one of the first dialyzers in Hawaii to get trained for home HD, and have been a big fan ever since! I really like how portable my machine is."*

Due to scar tissue, peritoneal dialysis was never an option for me. Perhaps, in the future, I'd like to give a transplant another try.

My mom has been my "rock." She urged me to learn all I could about life on dialysis from the very start. When I was at the doctor and first learned that my kidneys were failing, he turned to my mom and asked her what she wanted to do. She told him, "Don't talk to me, *she's* your patient." She has been by my side, through thick and thin, ever since.

A few years ago, I married a wonderful man, a Navy Senior Chief. We move every 3-4 years. I guess the Navy is in our blood now, since my 19 year old son recently joined the Navy, too!

Doing home hemodialysis (HD) means now I only have to change my clinic when we move, not my



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## TINA HARRISON

LOTS OF OPTIONS *CONTINUED*

mode of treatment. I started on home HD about 1-1/2 years before we went to Hawaii. When we got our orders, I chose my center based on the fact they were working on a home program. It took me a year, but I fought for the option of my choice, home HD. I finally went back home for my treatments. In fact, I was one of the first dialyzers in Hawaii to get trained for home HD, and have been a big fan ever since! I really like how portable my machine is.

In fact, I sometimes work as an ambassador for home HD. I visit other clinics and meetings to talk, and my advocacy work for kidney disease got me elected as President of the Board of Home Dialyzors United. I plan to work on issues that affect people who do all types of home treatment.



## CONCLUSION

The key to feeling well and staying independent is choosing the right treatment option. If you go online, a free tool called My Life, My Dialysis Choice ([www.mydialysischoice.org](http://www.mydialysischoice.org)) will let you choose your values and see what may be the best fit for YOUR life.

### HOME TREATMENTS COMPARED: PLUSES +

	CAPD	CCPD	Conventional HHD	Daily HHD	Nocturnal HHD	In-center HD
More-normal diet and fluids	✓	✓	✓	✓	✓	
More dialysis to feel better			✓	✓	✓	
Work-friendly treatment	✓	✓	✓	✓	✓	
Puts you in charge	✓	✓	✓	✓	✓	
You're not around sick people	✓	✓	✓	✓	✓	
Fewer ups & downs in how you feel	✓	✓		✓	✓	
Portable - take it with you	✓	✓		✓		
Flexible - suits your schedule	✓	✓	✓	✓		
Available in every state	✓	✓	✓*	✓**	✓****	✓
Needle-free treatments	✓	✓				
Have your days free		✓			✓	
Learn it in a week or two	✓	✓				
Fistula likely to last longer			✓	✓	✓	

### HOME TREATMENTS COMPARED: MINUSES -

	CAPD	CCPD	Conventional HHD	Daily HHD	Nocturnal HHD	In-center HD
Need to visit clinic 3 times a week						✓
Supply storage space needed	✓	✓	✓	✓	✓	
Infection is a risk	✓	✓	✓	✓	✓	✓
Can affect body image	✓	✓	✓	✓	✓	✓
Weight gain from dialysate	✓	✓				
Limits swimming, tub bathing	✓	✓			✓****	✓****
Lack of privacy						✓
A partner is needed			✓	✓	✓	
Takes several weeks of training			✓	✓	✓	
Plumbing/wiring may be needed			✓		✓	

\* Except WY \*\* Except MT \*\*\* Except MT, ND, RI, SD, VT, WV, WY \*\*\*\* If dialyzing with a catheter