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## Nocturnal Home Hemodialysis: Patients' Personal Experiences

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*Joyce Cagle, Margaret Horsley, Howard Scott, Christine Scott, Carolyn Lattimer, Samuel W. Smith, Jr., Maxine Diggs, Cecil Fulton, Sheila Walthalle*

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### Joyce Cagle

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Birth date: 03/04/1943  
Sex/Race: Female/White  
Peritoneal dialysis: 10/1989–11/1993  
Transplant: 11/1993–03/1994  
Peritoneal dialysis: 04/1994–08/1996  
Hemodialysis: 08/1996–09/1997  
Nocturnal home hemodialysis training: 09/05/1997–10/04/1997  
First home treatment: 10/05/1997

1. Chronic glomerulonephritis
2. Hypertension
3. Repeated gastrointestinal bleeding secondary to gastritis
4. Status post (S/P) parathyroidectomy

In the spring of 1997 I learned that an experimental program, nocturnal home hemodialysis (NHHD), was being tested in Toronto, Canada. The reports indicated that patient quality of life was greatly improved and that many patients were returning to work and experiencing a feeling of well-being.

Dialysis at best is a mixed blessing: on the one hand, it keeps me alive, but on the other hand, factors such as nausea,

high blood pressure, and fatigue limit one's ability to fully enjoy day-to-day life. Some days it seems as if I'm just getting by. Is NHHD a viable alternative? Does it improve life?

When Dr. Lockridge told me about this new treatment option and the fact that he was very interested in implementing the program in Lynchburg, I was very interested in participating.

At the same time I was skeptical. Could the excellent results the Canadians were reporting be true? It seemed too good to be true, but with a lot of thought and a little doubt I decided to give NHHD a chance.

In late August I had the catheter placed and began training a week later. The training was 4 days a week for 5 weeks. Practice, practice, and more practice was the order of the day. By the time I was on my own, I felt confident that I could operate the machine.

It did take a while to get used to sleeping with the machine in the room. But once I got used to it, I slept very well with few alarms. And the Canadian reports of well-being weren't exaggerated. I used to think of myself as being sick with a

not-too-promising future. Now I feel well, have confidence, energy, and a feeling of well-being that is hard to convey to others. I feel that NHHD has given me my life back. Prior to NHHD my life consisted of illness, lack of energy, poor outlook, and every major holiday spent in a hospital. There were many trips to the emergency room with life-threatening problems, usually on Friday night, prompting my husband to jokingly comment, "We need to go other places once in a while."

When I began dialysis in 1989, both my sons were in college, and my life goal at that point was to see them both graduate. After reaching that goal, everything was pretty much one day at a time. Since beginning NHHD my outlook has improved so much that I now am thinking long-term: grandchildren graduating from college, great-grandchildren, the list is endless.

Medically, everything changed for me almost immediately after beginning NHHD. My blood pressure dropped to a normal range and has remained so. Prior to NHHD I took a combination of as many as five different medications to control blood pressure; now I take none. My energy has returned, and once again I have confidence in myself and my abilities. I have had no hospitalization in the 16 months I've been on NHHD, and no more Friday night dates with my husband in Lynchburg General's emergency room.

I recommend NHHD to anyone who is interested. I can only hope that this therapy will be available to many other dialysis patients in the future. For that to happen, physicians, patients, and legislators need to know this is an outstanding treatment option that can only lead to better health for the patient.

### Margaret Horsley

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Birth date: 08/09/1957  
Sex/Race: Female/Black  
Peritoneal dialysis: 12/1988–10/1989  
Hemodialysis: 10/1989–09/1990  
Transplant: 09/1990–09/1992  
Hemodialysis: 09/1992–10/1997  
NHHD training: 10/16/1997–11/22/1997  
First home treatment: 11/23/1997

1. Focal glomerulosclerosis
2. Hypertension
3. S/P parathyroidectomy

I am a hemodialysis patient. I run 6 nights a week, 7 hours a night. I am going to tell you the way I feel about things. When I first started dialysis, I thought I couldn't make it. I





was scared of NHHD, but I read about it and the doctors talked to me about it. I said I am going to think about it first. So I thought about it and then I told them I would give it a try. Ever since then I have been doing just fine on hemodialysis.

Now, I have been on NHHD for about one year and three months. I enjoy dialysis at night. I feel so much better and I have my days free. I do a lot of walking. I went out and tried to find a little job. I had a small job but didn't get enough hours. I was

more tired after I had to work. Now my doctor told me that I have "sugar," so they are working with me to get it down.

My husband sticks by me in every way. I tell him something is wrong, and he is there by my side. He makes sure that I have something to drink or eat. Even my medicine, too.

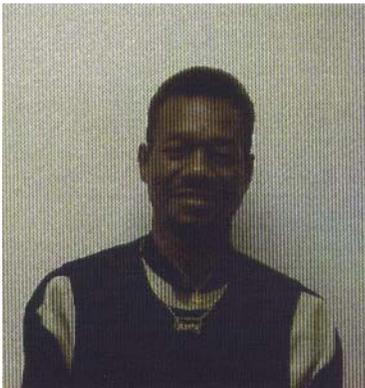
The nurses and doctors are very nice. They are a wonderful group of people. I can't ask for a better group.

**Howard Scott**

Birth date: 10/10/1956  
 Sex/Race: Male/Black  
 Hemodialysis: 09/1991–10/1991  
 Peritoneal dialysis: 10/91–12/92  
 Transplant: 12/1992–03/1993  
 Peritoneal dialysis: 03/1993–01/1998  
 NHHD training: 01/05/1998–02/06/1998  
 First home treatment: 02/08/1998

1. Membranous glomerulonephritis
2. Hypertension
3. Polyclonal lymphoma associated with transplant
4. Supraventricular tachycardia recurrent requiring ablation of aberrant pathway

**M**y nickname is Binky. I'm 42 years of age, married to a wonderful and understanding wife and friend, Chris.



On January 5, 1998, I started on NHHD. What a blessing. It took me about 2 months before I was feeling some good results. I started waking up early in the morning, started walking, then I began to run. Now I love to eat and my eating habits are very good, which makes me so happy. On peritoneal

dialysis my appetite would come and go. One or 2 weeks my appetite would be OK, then the following week my appetite would be very poor. That made me unhappy, because I couldn't eat the way I wanted to. Then the next thing I know, I'm crying at the table because the food would be in front of me, but I couldn't eat it because I lost my appetite. I don't have that problem anymore, since I'm on NHHD. My blood pressure is excellent. I sleep well, stay happy, and love shopping at the mall, which I didn't enjoy at one time. But the biggest thing that has changed since I've been on NHHD is that I love life again. The small things in life mean so much to me. Now, even when it rains, every day is a good day for me. I say this because bad weather used to depress me. Now life is a new beginning for me. I feel that I can be a productive person in life once again.

Anyone who is on dialysis or about to start dialysis should give NHHD a try. You will be blessed with life again.

**Chris Scott**

**M**y husband is a NHHD patient. He has been on the program a little over a year now and is doing great. We have had no more hospital visits. His eating habits have improved a lot. He eats all the time, and he thinks I should eat every time he eats! His attitude on life in general has improved greatly. He feels that he has something to live for and to look forward to. We take short trips, go walking and shopping, and just visit our friends more. I believe we have been truly blessed with this program. And we feel that if others would give it a chance they would feel blessed just as we do.

**Carolyn Lattimer**

Birth date: 09/18/1965  
 Sex/Race: Female/White  
 Hemodialysis: 09/1983–10/1985  
 Transplant: 10/1985–11/1997  
 Hemodialysis: 11/1997–02/1998  
 NHHD training: 02/09/1998–03/13/1998  
 First home treatment: 03/16/1998

1. Focal glomerulosclerosis
2. Hypertension
3. Tophaceous gout

**I** was diagnosed with focal glomerulosclerosis at the age of 15; three years later I began conventional hemodialysis. I was a self-care patient, meaning I set up my machine, monitored my run, returned my blood, and cleaned my station. I ran 3 times a week initially for 3 hours a run, which over time progressed to 4 hours. I attended college full-time and had a part-time job on the campus. I maintained this routine for approximately 2 years. Muscle cramps and severe hypotension became commonplace, something to be expected. I could also expect to miss at least one class per week because of post-dialysis malaise and lethargy. The strict renal diet was just

something that had to be done. The consolation was that, at that time, we were allowed to eat during our dialysis runs, which allowed us to enjoy normally taboo foods and drink all we could until the last 2 hours of run time.

After 2 years of dialysis, I was called for a transplant. The transplant did not function as optimally as some but did keep me off dialysis. My transplant lasted for 12 years until chronic



rejection so diminished its function that I was required to consider dialysis again. During that 12 years, I graduated from college with my class in 1987, changed jobs once, and got married. I also enjoyed the freedom that transplants bring with regard to diet, travel, employment, and involvement in church activities. During that time, I developed osteoporosis

from prednisone, had bilateral cataract surgery, gained weight, and maintained a variety of treatments for various skin infections and skin lesions.

I was not looking forward to restarting dialysis despite the side effects from immunosuppressive drugs. I had enjoyed a relatively normal lifestyle for 12 years and did not want to return to the restrictive diets, sacrifices of time, and generally feeling unhealthy that I knew dialysis would bring. Besides, I had my own business to operate and could not afford, literally, turning over 4 – 5 hours of work time to dialysis, as well as giving up the ability to function well. Then I was told about another option: NHHD. With this modality, I was told I could dialyze at night while I slept for 7 hours, 6 nights a week. My diet would be more liberal because I was dialyzing every night. Because it was for 7 hours, it would be a slower dialysis and more “gentle”; therefore, I would not suffer the debilitating cramps, hypotension, and lethargy associated with conventional dialysis. I was also told that patients did not want to miss a treatment. I asked to be signed up for the 5-week training period as soon as possible.

I went home with my machine in March 1998 and have been doing NHHD for almost a year. I have never had cramps or hypotension coming off the machine. I have never had “down” days to recover from dialysis. My diet consists of every otherwise taboo food, and I drink as much as I want. I walk and do weight and strength exercises.

I continue to enjoy a very happy and full marriage, and I work at my home job seemingly all the time. I also work part-time at the local hospital and am involved in church activities. The only thing I do not do is travel for extended periods. That really is not a concern because I am somewhat of a homebody. We have taken a long weekend to get away. I do not like to miss a treatment, which for me averages 8 – 9 hours (I like my sleep).

I have more energy and motivation than I ever had before or during my transplant. My creatinine is actually better than when I had the transplant (1.6 – 2.1 mg/dL). My blood urea nitrogen is less than 10, and my uric acid is almost zero. I am off the allopurinol, and all the gout crystals have dissolved. I am currently undergoing treatment for osteoporosis, and my skin has entirely cleared. I am on almost no medications. All antihypertensives have been stopped. All immunosuppressants have been stopped. I take three nutritive supplements plus coumadin to keep my catheter working well. My monthly drug bill has gone down from \$400 per month to around \$50. I have not even had a head cold during this past year. Erythropoietin injections have decreased from as high as 5000 U twice a week to 2000 U per week. I have discontinued monthly intravenous iron for an indefinite period.

I am completely impressed with the effectiveness of NHHD. Overall, my course of treatment has been uneventful. I am also impressed with the machine we use. I can go to sleep at night and be completely confident that the machine is monitoring my run effectively. I enjoy feeling well and healthy, and at 33 years of age, I am glad I can look forward to a long and productive life because of it.

#### Samuel W. Smith, Jr.

Birth date: 02/26/1929

Sex/Race: Male/Black

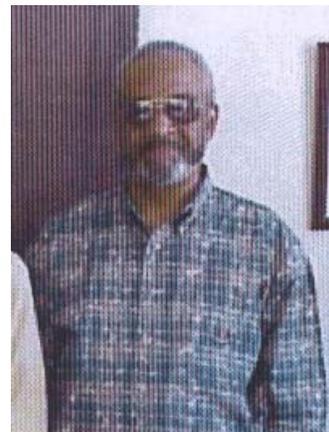
Hemodialysis: 06/1997–03/1998

NHHD training: 03/16/1998–04/24/1998

First home treatment: 04/26/1998

1. Nephrosclerosis
2. Hypertension
3. Coronary artery disease S/P coronary artery bypass
4. Congestive heart failure secondary to fluid overload

I started dialysis in June 1997, in Lynchburg General Hospital, after having open heart surgery. That’s when my kidneys failed. I started dialyzing in-center 3 times a week, 4 hours each day. My wife transported me to and from the center for 10 months because I was unable to drive. I stayed very tired, weak, and had very little energy. I didn’t even feel like going to the store.



In March 1998, I started training for NHHD. I dialyze 7 hours, 6 nights a week, and I feel like a different person. To be honest, I feel better now than I did before I had open heart surgery. I can eat most anything I want, I take a morning walk, and I help my wife out some. My wife is very pleased with

NHHD. She always tells me how glad she is that I feel better and also look better.

I recommend NHHD to anyone who has to be on dialysis. I hope I can stay on NHHD.

**Maxine Diggs**

Birth date: 10/17/1951  
 Sex/Race: Female/Black  
 Peritoneal dialysis: 01/1997–06/1998  
 NHHD training: 06/29/1998–08/08/1998  
 First home treatment: 08/09/1998

1. Chronic glomerulonephritis
2. Hypertension

In the last 10 to 15 years the treatment of renal failure has made leaping advancements for patients. You see, 11 years ago my mother was on dialysis. She started in June and on July 14 she passed away.



When I was told 3 years ago that I would have to start dialysis, I thought the same would happen to me. Well, it is 3 years later and I am still here. I work at a full-time job as an assistant principal at an elementary school in Pittsylvania County Public Schools, Virginia.

I have been a dialysis patient for 3 years. Initially, I was on peritoneal dialysis. In June 1998 I trained for NHHD. When I was on peritoneal dialysis, I was

sluggish and tired all the time. I did not have the energy to participate in family activities or my personal hobbies and civic duties. I just wanted to sleep at every opportunity I had. My time was spent sleeping and working. There were times when I was too tired or sleepy to eat.

At present, I am on NHHD. I dialyze 6 nights a week, 7 hours each night. I cannot begin to tell you how much better I feel today. I have a very good appetite and energy to spare. My medications consist of vitamins, iron, coumadin, and heparin. I have the energy to do the things I like. I travel to visit my daughter, walk when the weather permits, attend church, visit friends, and attend civic meetings.

No amount of money can compensate the doctors, nurses, and staff at the Lynchburg Dialysis Center. A nurse or doctor can be reached 24 hours a day. They are caring, patient, and considerate. They are involved in the total person, not just the physical illness. They constantly ask questions to find out about a patient mentally, socially, and emotionally.

**Cecil Fulton**

Birth date: 11/14/1948  
 Sex/Race: Male/White  
 Hemodialysis: 10/1996–10/1998  
 NHHD training: 10/05/1998–11/16/1998  
 First home treatment: 11/17/1998

1. Diabetes mellitus type II
2. End-stage renal disease (ESRD) secondary to diabetes mellitus
3. Coronary artery disease S/P coronary artery bypass
4. Peripheral vessel disease secondary to diabetes mellitus, S/P bilateral below the knee amputations
5. Severe peripheral neuropathy secondary to diabetes mellitus
6. Diabetic retinopathy

I have been a diabetic since 1976. This is a terrible disease that can rob you of much of your quality of life, and even life itself if left untreated.

About 4 years ago I had gotten to the point of feeling tired and exhausted most of the time. I was very lethargic,



very much overweight with fluid, had almost no energy, and my quality of life was at an all-time low. On a scale of 1 to 10 it was about a 2 or 3. I had just about given up on ever getting any better and felt I had no hope. I was treated with medicine until my kidneys began to fail in 1996; this is when we started talking about dialysis, and in September

1996 I started hemodialysis at Lynchburg Dialysis Center, 3 days a week, 4.5 hours/day. After about 3 to 4 weeks of these treatments I began to feel better and thought maybe there was hope after all. I continued these treatments until October 1998 and was feeling much better. My quality of life was now about 5.

I was introduced to NHHD in October 1998. I was given the option of trying this new dialysis at home or continuing in-center dialysis at that time. I chose NHHD for a number of reasons. First, I do my dialysis at night while I am sleeping, so there is no loss of quality hours during the day. Second, there is very little restriction on diet or fluid intake because dialysis is done more often (6 nights/week, 7 hours/night). Third, this provides a better and more even blood cleaning and purification. This has raised my quality of life to about 8.5 at this time. I feel great, and I don't feel like a sick person anymore.

It takes approximately 6 weeks of training at the Dialysis Center (5 days/week) to become qualified to do NHHD. My

wife and I were trained by a great staff of instructors. We were assured that the staff would not allow us to graduate from our training class until we were able to pass all the tests and, most importantly, until my wife and I were confident that we could do this on our own at home.

Diabetes is a killer and a robber. It has robbed me of two legs and several years of my life quality before dialysis. At this point in my life, I am 50 years young, and I feel great and am enjoying life again.

### Sheila Walthalle

Birth date: 05/06/1972

Sex/Race: Female/Black

Hemodialysis: 04/1996–11/1998

NHHD training: 11/16/1998–12/18/1998

First home treatment: 12/21/1998

1. Systemic lupus erythematosus
2. ESRD secondary to diffuse proliferative glomerulonephritis secondary to systemic lupus erythematosus
3. Hypertension
4. S/P above knee amputation of the right leg secondary to vasculitis
5. Bilateral avascular necrosis of the hips

I'm a dialysis patient. I was on dialysis at the unit for 4 years until something came along that was much better for me: home dialysis. I want to let others know how I feel and what it is like being at home on home hemodialysis. First of all, I love being at home and not having to go to the unit 3 times a week. I feel like a million bucks; if only I had that million bucks now. I'm glad someone took the time and taught me to do something on my own at home. It is amazing how I feel. I'm more outgoing. I want a good job, and then I want to be a

foster mother. All those things I can do with a little help from my family and friends at dialysis, now that I'm at home.

There are a lot of people having a hard time thinking about what it would be like to do home dialysis and thinking that a lot of people can't do it.

Well, friends and family, I'm here to let you know that it is safe. And what you need to do is talk to the training staff. They will teach you how to get to know your machine and how to become a real buddy with it. You don't have to train a long time, and you can always have a partner to train along with you. I know I have a partner to help me out. He's someone special in my life who has been there for me for a long time and who will be with me for a long, long time to come.

If you and your family are having second thoughts about doing this, well don't. I know it is easier to say than do, but I had the same thoughts and words that you all have. I talked to some of the people who were already doing it, and saw how they felt. It sounded great to me.

I hope to be on home hemodialysis for a long time. Now I am glad I did it. I have a great doctor who keeps a real good watch over me and I can talk to him like a father. I'm not on all those pills I used to take. I'm down to five pills a day. I'm eating well. I can eat what I want and have no fluid restrictions at all.

Home dialysis is the best thing that ever happened to me. I miss all my friends from Bay A, but I don't think I want to go back.

