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Testimonial of a patient undergoing long nocturnal home hemodialysis on a conventional cyclor.

(Témoignage d'un patient en hémodialyse longue nocturne à domicile sur cycleur conventionnel.)

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Summary

As a dialysis patient myself, I share here, with his consent, the story of Laurent, a 50-year-old dialysis patient who was diagnosed with congenital malformative uropathy at the age of 2. At the age of 25, he was diagnosed with chronic kidney disease (CKD) and received hemodialysis for 5 years.

In 2003, Laurent underwent a kidney transplant in Amiens, resulting in a 17-year period without major complications. After this transplant period, the choice of modality led him to opt for home hemodialysis. With the support of his partner, he learned the necessary procedures.

After more than a year of home dialysis, Laurent discovered long nocturnal dialysis (LNHD) via social networks. After discussing it with his nephrologist, he tried LNHD at home, with 8-hour sessions 3 times a week, adapting to his and his partner's work schedules.

In the spring of 2023, water quality problems led him to switch to a low-flow dialysate cyclor. Technical complications, with the osmosis unit supplied with the low-flow cyclor, led him to return to dialysate bags, causing a feeling of fatigue equivalent to 3 4-hour dialysis sessions and other problems.

After unsuccessfully trialing other equipment, the technicians finally reinstalled an adapted water treatment system, enabling Laurent to return to the conventional generator with water treatment. He quickly regained his previous benefits, underlining the importance of adaptability and collaboration between the patient and the medical team.

In conclusion, home LNHD with a conventional generator and water treatment is currently the treatment mode best suited to Laurent's needs, enabling him to lead a near-normal life despite the complications. This underlines that caregivers should maintain the possibility of using conventional cyclors even if other new technologies are available.

Keywords : LNHD, Home dialysis, testimonial

Résumé

Dialysé moi-même, je partage ici, avec son accord, le parcours de Laurent, 50 ans, patient dialysé, débutant avec une uropathie malformative congénitale diagnostiquée à l'âge de 2 ans. À 25 ans, il découvre qu'il souffre d'insuffisance rénale chronique (IRC) et commence l'hémodialyse pendant 5 ans.

En 2003, Laurent bénéficie d'une greffe rénale à Amiens, bénéficiant d'une période de 17 ans sans complications majeures. Après cette période de greffe, le choix de la modalité le conduit à opter pour l'hémodialyse à domicile. Avec le soutien de sa compagne, il apprend les procédures nécessaires.

Après plus d'un an de dialyse à domicile, Laurent découvre la dialyse longue nocturne (HDLN) via les réseaux sociaux. Après en avoir discuté avec son néphrologue, il tente l'HDLN à domicile, avec des séances de 8 heures trois fois par semaine, s'adaptant à ses horaires de travail et à ceux de sa compagne.

Au printemps 2023, des problèmes liés à la qualité de l'eau le conduisent à passer à un cycleur à bas débit de dialysat. Des complications techniques, avec l'osmoseur fourni avec le générateur bas débit, le font revenir aux poches de dialysat, provoquant un ressenti de fatigue équivalent à 3 séances de 4 heures de dialyse, et autres problèmes.

Après des essais infructueux avec un autre matériel, les techniciens réinstallent finalement un traitement d'eau adapté, permettant à Laurent de revenir au générateur conventionnel avec traitement d'eau. Il retrouve rapidement ses avantages antérieurs, soulignant l'importance de l'adaptabilité et de la collaboration entre le patient et l'équipe médicale.

En conclusion, l'HDLN à domicile avec un générateur conventionnel et traitement d'eau est actuellement le mode de traitement le plus adapté à ses besoins, permettant à Laurent de mener une vie quasi normale malgré les complications. Cela souligne la nécessité de maintenir les cycleurs de dialyse traditionnels, même si de nouvelles technologies sont disponibles.

Mots-clés : HDLN, dialyse à domicile, hémodialyse, témoignage



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TESTIMONIAL

My name is Laurent. I'm 50, and I've been suffering from chronic renal failure for 25 years. I was born in 1973, at a time when prenatal ultrasound scans didn't exist. At the age of 2, faced with numerous infectious episodes, I was diagnosed with congenital malformative uropathy. Until I was 5, I underwent numerous hospitalizations and several surgical procedures at the Necker hospital (resection of a urethral valve and several bilateral urethral re-implantations), with medical follow-up until I was 9. I grew up not knowing that all this could have a medium- or long-term impact on my kidney function.

At the age of 25, shortly after landing a job as a production engineer, I suffered a gout attack following a 50 km bike ride. A blood test was prescribed, and I was diagnosed with CKD. I was told I had to undergo dialysis and be put on the waiting list for a kidney transplant. I was fitted with an arteriovenous fistula and shortly afterward began hemodialysis in the evening to enable me to continue working. I was on dialysis for 5 years.

In September 2003, I was transplanted in Amiens hospital. My graft functioned for 17 years without any major complications, enabling me to live a totally normal life. During this period, my fistula was reduced due to excessive flow, and then it became blocked. When I had to go back on dialysis treatment, the dialysis center (Chaumont, France) which was the closest to my home (23 km), no longer offered evening dialysis sessions; they were only in the morning or afternoon. This was not compatible with my job as a logistics manager, which I can't do part-time. The centers offering evening and/or night sessions are more than 1 hour's drive from my home. What's more, because of my history of abdominal surgery, I can't have peritoneal dialysis.

After consultation with my partner, I decided to undergo home hemodialysis. A new fistula was created, and while I waited for it to develop, I dialyzed on a catheter. I spent several months training at ALTIR in Nancy, 130 km from my home, where I learned how to puncture my fistula and use a conventional hemodialysis machine. At the same time, work was carried out in my home to install water treatment for dialysis in my office, which became my dialysis room. In December 2020, I started dialyzing at home, 4-hour sessions, 3 times a week in the evening after coming home from work. My partner helps me connect and disconnect the machine. She manages the maintenance of the water treatment (water tests before each session and filter changes every month) and the logistics of equipment deliveries and technician interventions.

After more than a year of following this time-consuming and tiring schedule, I discovered long nocturnal dialysis (LNHD) on social networks via Fabrice HURÉ. I discussed it with my nephrologist and decided to try LNHD at home. The sessions consist of 3 8-hour sessions a week, from 9 pm to 5 am, to fit in with my working hours (8.30 am to 7 pm, 5 days a week) and those of my wife (6.45 am to 6.25 pm, 3 days a week). Within the first few weeks, I felt less tired. My appetite increased. My hyperphosphatemia was regulated, even allowing me to stop chelation therapy. I could play sports more easily. My blood pressure stabilized, allowing me to stop taking antihypertensives.

In the spring of 2023, after a year of LNHD, my nephrologist, concerned that the nitrate level in my water was a little too high for dialysis, suggested that I replace the conventional generator with a low-flow dialysate cyclor (Nxstage®), which would enable me to continue LNHD without depending on my city's water. I was taking a one-week training course with my partner. The generator and consumables were exchanged at my home, and the water treatment was removed. As soon as I moved in, the cyclor and the associated water purification and dialysate preparation system broke down one after the other, forcing me to change the machine and the osmosis unit several times. After a month, faced with another breakdown, I decided to switch definitively to dialysate bags (9 bags of 5 liters per dialysis), abandoning the supplied filtration system, which was far too time-consuming to prepare, with its alarms and breakdowns. In use, the cyclor itself seems less suitable for HDLN than my previous machine: firstly, the noise (with its frequent tests), which disturbs sleep; secondly, it's not very reassuring, with its many alarms, some of which are unexplained; and thirdly, its ergonomics could be much improved (not very intuitive to use and interface not very functional). At the same time, I felt more tired than before (despite an identical 8-hour dialysis schedule 3 times a week), and my appetite was diminishing with the return of nausea and restlessness in my lower limbs. Faced with the deterioration in our motivation for home dialysis following this change of equipment and technical complications that were incompatible with our tight schedule (work and dialysis), the ALTIR nursing and technical team looked for another solution.

In mid-July, after tests in their workshop, the technicians came to reinstall a water treatment system with the addition of a nitrate-removing resin; they also brought back a conventional generator and took water samples for analysis. Several weeks later, the results of the water samples proved it was suitable for dialysis. At the end of August, with the agreement of the nephrologist and the pharmacist, I resumed my dialysis on the conventional generator with water treatment. From the very first sessions, I felt much better again, rediscovering all the advantages and benefits of LNHD at home. As I await a second kidney transplant, LNHD at home with a conventional generator with water treatment is currently the most appropriate form of replacement therapy for my needs, enabling me to live an almost normal life and take regular exercise (1h running and 1h20 swimming a week).

I would like to take this opportunity to thank, in particular, the medical and technical team at ALTIR, without whom all this would not have been possible, for their care, assistance, and adaptation to various events, always in the patient's interest; and my wife, for her attentive help, patience, and strength on a daily basis, helping me both medically and psychologically to move forward positively in this period of transition towards transplantation – in other words, everybody who makes my journey so much lighter and enables me to enjoy my life without any regrets about the complications that have been and still are in my path.