

I am 49 years old, live in a small village, in France, with my wife and two teenagers.
I am a school teacher and very sporty.

In 2019 I suffered from bouts of tiredness, which I chalked up to my job, which requires a lot of energy. Following this, I had oedema marks on my legs, cramps when I played badminton and my cholesterol level had increased. My GP advised me to eat less salt and less fat, although I already had a reasonably healthy diet!

A few weeks later I started to have stomach pains, which my doctor attributed to gastroenteritis. The pain kept increasing and I was becoming more and more fatigued. Finally, thanks to blood and urine sampling, I was diagnosed with nephrotic syndrome. I was rushed to hospital for a kidney, then bone marrow biopsy. I also underwent a CAT scan and a heart ultrasound. I received the diagnosis one week afterwards, which was 4 months after the first symptoms: AL amyloidosis affecting the kidneys and liver. I was told the news by my nephrologist, who explained the treatment I was going to follow: 8 months of chemotherapy

Initially I was floored, I didn't want to die, I said to myself that I wanted to see my kids grow up.... My doctors explained that there were some effective treatments. Therefore, I prepared myself mentally to fight this illness, to get through the treatment and beat it.

Unfortunately, despite the chemotherapy, my kidneys continued to quickly deteriorate, and I was kept in hospital several more weeks. During this period, I watched my body deteriorate day by day, which was really tough for me emotionally, because my situation was continuing to get worse despite what my doctors had said. Fortunately, I received the support of the hematology department's psychologist, who I still see now. The doctors were quickly bringing up the possibility of dialysis, or even a kidney transplant. So, in September 2020 they operated on me, creating a fistula in the arterial vein on my right wrist (afterward a failed attempt on the left arm).

The idea of having to undergo dialysis for the rest of my life really broke me, I was sure my life would never return to normal.

My body no longer responded to my brain - I struggled to walk around my garden. It got to the point where I only thought about moving in my imagination, with my eyes closed. I could no longer drive, and I struggled with no longer being independent - I cried a lot. When I was able, I did yoga and meditation and did fine arts in a support group for patients and that helped me a lot.

In April 2021, we started the first steps with the transplant center in my region - inquiring about the possibility of receiving a transplant from a living donor - my father and my wife offered to be the donors.

So, in November 2021 I underwent second line treatment to improve the health of my liver.

I stayed on the treatment for 18 months. I underwent a bone marrow differential cell count during my treatment, which showed that there were still plasma cell clones in my bone marrow, and so I continued the treatment.

Thanks to this treatment, which I tolerate reasonably well, the notion of dialysis and transplants are behind me. After several months I regained my energy and my kidneys repaired little by little. Now I can do activities in nature again, walking, electric cycling, Irish flute, choir... I'm even thinking about returning to work part-time.

Throughout my treatment journey, I always wanted to know the truth about my state and my treatments. I'm always active in taking charge of my health; during consultations I ask questions and sometimes ask for scientific explanations. My doctors have never judged me and I thank them for it.

The French Association Against Amyloidosis organises monthly virtual cafes, which have been a huge support, and I volunteer at different outreach/testimony events they organise.

In the 3 and a half years since my disease was diagnosed, I've been through several different physical and mental states. It is an enormous traumatic event in my life.

I know that I'll live with amyloidosis for the rest of my life. However, unlike in the first years, I can feel my body again, which is recovering, and I'm able to think of the future living with this disease and its relapses. I know there are some treatments which work, that progress will be made in research and that other effective treatments will be found. I keep hold of these positive thoughts to help me get through the future. I'm taking up holiday projects and work projects again. I've taken up beekeeping and I am active in multiple groups. Even if I feel fragile and vulnerable - like one bad thing could tip me over the edge, I savour the feeling of living again!

Sincerely,