I am a woman in her fifties living in the suburbs of Paris, France.

I was diagnosed with multiple myeloma / AL amyloidosis in 2018 but I had been living with minor symptoms four years or so before the diagnosis was established. During this period, I consulted various specialists: my family doctor because I was unusually tired, a cardiologist and a pneumologist because of an increasing shortness of breath and a gastroenterologist to find out why my stomach always felt so full that I could not eat more than a small amount of food. I also went through various medical tests that had led to nothing.

Before that, I had been diagnosed with monoclonal that had remained dormant until after amyloidosis was revealed and since then, I had been under the surveillance of a professor in hematology in a Parisian hospital. Although I had told him several times about that permanent shortness of breath, he never cared to consider it seriously and told me off for having practiced useless and costly medical exams. So much precious time wasted!

AAL was finally diagnosed at stage 4 (the highest) and I was left in the care of a Parisian hospital team of cardiologists, specialized in amyloidosis. I was soon implanted with a defibrillator + pacemaker and started 11 months of chemotherapy which did not meet the success we had hoped for. Another treatment was then successfully tried and allowed autologous stem cell transplant.

Since then, treatment has been delivered to me every month. The hematological response is complete, and the light chains are being kept low.

I tolerate the treatment well and have very few side effects except occasional fatigue or possible digestive disorder. Thanks to the educational programs established by the hospital cardio team and therapy sessions in a rehabilitation center for people who suffer from heart I have learned to know my disease well and I feel confident enough to handle unexpected problems without worrying too much.Knowing that I can also rely on the hospital cardio or hematological teams and get in touch with them in no time is also of great psychological help. I am now back to what I consider a normal life. I have given up skiing and all physical activities that could cause a break of my bones, walking slopes quickly gets me out of breath and I cannot run but I walk several miles at a quick step every day to try and stop the deterioration of my heart.

Swallowing 12 to 15 pills every day, giving myself injections, avoiding salty food and the daily checking of my weight have become a habit which does not bother me anymore.

I am still very wary about Covid which I consider as double punishment for us, patients. It's the sword of Damocles that adds to possible fits of anxiety. Yet, I have taken it upon myself to resume a social life, go on holiday and fly to foreign countries.

Before AAL, I was a volunteer helper, teaching young patients in hospitals and working for the Red Cross. Being in contact with a poor population and ill people is now considered as high-risk activities which I sadly had to give up.

However, being now in remission and feeling quite fit, I have joined the French Association Against Amyloidosis so as to help other patients. We encourage talking and sharing with other patients which is a good way to overcome anxiety and depression. I try to follow up on the latest research and attend congresses.

Seeing me now is a relief to my family who first saw me break down after the announcement of the diagnosis. They were told that my life was at stake and a heart transplant was first contemplated (that finally turned out not to be necessary). They helplessly witnessed the undergoing of all the exams and treatments that had painful side-effects during that first year, the ups and downs of my medical results and the diffcult times of the stem cell transplant. One of my children was deeply affected by the situation, broke down and stopped studying.

Things are now settled and I'm feeling very grateful for all the help I have got from the very beginning from my medical team and their dietician, psychologist, social worker...

I have always been well advised and taken care of. I trust them and thank them for their concern and their kindness.

Nurses of advanced practice have been assigned to both wards (cardio and hematology) which is of considerable help for the patient. They are a precious link between patients and doctors. Being treated by a well-organized team, there is not much more I could personally wish for myself.

Knowing that the number of patients with amyloidosis is increasing and so as to avoid misdiagnosis or diagnostic delay, I hope we soon find a way to get general practitioners widely informed, as well as all the physicians specialized in organs or tissues that are currently targeted by amyloid deposits.

Working patients with a rare disease have to face complex administrative journey and I wish the Health Minister Department would work on making things easier for them.
Having been treated for over 5 years, I have benefited from the latest medical research which has considerably eased my condition and hopefully extended my life expectancy.

So, my hope is for continuing progress of the research until amyloidosis becomes curable and ends up with the discovery of what is at the root of it.

Until then, I am sending you my deep gratitude for what you have done for me.

Yours sincerely,

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