



Patients Speak Mr. Henri Cuypers: My Experience with Zytiga

Mr. Henri Cuypers, a member of the Board of Us Too Belgium, talks to *Prostatepedia* about his prostate cancer journey and his experiences with Zytiga (abiraterone).

What was your life like before prostate cancer?

Mr. Henri Cuypers: I enjoyed life very much. I retired as an army helicopter pilot at the age of 54. Rather soon. My wife and I traveled a lot and we had an active social life and a lot of friends. Windsurfing and playing golf were my sport activities. We had a healthy sex life.

When and how were you diagnosed with prostate cancer?

Mr. Cuypers: I was diagnosed with metastatic prostate cancer in June 2001. Seventeen years ago. All patients have different stories, but mine was particular. I had pain in my right leg. Since I was very active, my doctor thought this was due to my sporting activities. The pain increased. I had my blood stream in the leg checked with no results. Controlling the nerve system did not show any deficiency. The pain increased so much that I couldn't get from the first floor to the second floor. It was enough. I went to the emergency department of my hospital. I had an MRI, a bone scan, and a bloodtest. I had a PSA of 42. I had prostate cancer with a metastasis in my L5 vertebrae. I even had a fracture.

Most people learn about their prostate cancer diagnosis from their urologist; I learned about my diagnosis from a neurosurgeon. I had no time to consider which treatment was best. They even put me in a wheelchair, fearing the L5 would break completely. I still had a biopsy after that which revealed an aggressive Gleason 8 tumor.

What was your initial reaction?

Mr. Cuypers: The diagnosis came as a complete surprise. I panicked and did not understand a word of what the doctor said. A cousin of mine had died from prostate cancer a few years before, so it's understandable that I really feared for my life. My wife was present when I was given the news and she told me afterwards what had been said.

I was wondering how long I had to live and asking everyone but no one was willing to answer that. Then I looked up the statistics: I had a 10% chance of living longer than five years. That was the beginning.

What types of treatments did you receive?

Mr. Cuypers: It's a little bit complicated, as you can imagine. The basic treatment I got was hormonal therapy and after 17 years, it still is. First, I got Decapeptyl (triptoreline) and Casodex (bicalutamide) against an initial flare. Because of the mets in my bones, I was also irradiated; I had ten sessions. This reduced the pain to an acceptable possible level, but I needed a painkiller for six months. Then I did without the pain killer. Since the hormonal treatment weakens the bones, I had to take Zometa (zoledronic acid) bisphosphonate infusions (149 of them) and recently started Xgeva (denosumab) injections. After initial treatment, I went into remission. But then my PSA climbed very slowly. It took seven years to go to 7.6. That was when the doctor added Casodex (bicalutamide). I went into a second remission. This remission lasted six years but ended with a PSA of 154 and a one month doubling time. I had a Choline PET scan that showed mets in my ribs, lungs, and liver. The one in my liver was 3 centimeters, not very small. That was a critical point, of course.

When did you start taking Zytiga (abiraterone)?

Mr. Cuypers: At the end of 2014, I had to choose how to deal with that situation. My choice was between Taxotere (docetaxel) chemotherapy, Xtandi (enzalutamide), or Zytiga (abiraterone). I was afraid of the side effects of the chemotherapy. And I had read in patient blogs that many have bad experiences with Xtandi (enzalutamide). Together with my doctor, we decided on Zytiga (abiraterone) in February 2015. At that point, I stopped taking Casodex (bicalutamide).

What was taking Zytiga (abiraterone) like for you?

Mr. Cuypers: My response to Zytiga (abiraterone) was fantastic. In two months' time, my PSA was undetectable, that is below 0.01. What's more important is that there were no more mets on the control CT scans. They had vanished, which was fantastic. This third remission has now lasted 44 months. A minor disadvantage of the Zytiga (abiraterone) is that you have a threehour window during which you cannot eat: two hours before taking the pills and one hour afterwards. That's not too difficult. My blood pressure increased, but to acceptable levels. I have edema around my ankles.

But the bigger issue is that I have fatigue. My hemoglobin has dropped from 10 to a little bit more than 7.

I have just had my first blood transfusion last week. I feel tired now when walking up stairs or on long walks, but driving my car is no problem. I've got an electric bike so that allows me to drive around. I even managed to have a city trip with my wife last month. In Belgium, there is no financial aspect to getting Zytiga (abiraterone) since our national social security pays for it.

Do you have any advice for men who have been prescribed Zytiga (abiraterone)?

Mr. Cuypers: Europe might be a little bit different from the United States. In the United States, I think some go for a genetic test to assess the chances of the Zytiga (abiraterone) working. Here, I took Zytiga (abiraterone) straightaway, especially since I did not have to pay for it. I advise my fellow patients to respect the daily non-eating window of three hours. Once, I did not do so; my blood pressure went up. It's best not to eat during those three hours. As much as possible, you have to take the pills at the same time every day, but after a while, the active product is in the blood stream, and I have been told that a one-time shift of four hours is acceptable.

Try to keep your physical condition as healthy as possible. But that's easy to say. Wear the compression socks. I feel a difference when wearing those socks for the edema. Measure your blood pressure daily.

Ask your doctor if the vitamins B12, D, and folic acid are useful for you. They are not necessarily useful for everybody, but those nutritional supplements might help in producing red blood cells, which I'm lacking.

(This means I'm lacking oxygen in my muscles and in my brain.)

Is there anything else you want to say about your own experience?

Mr. Cuypers: I'm a member of the Board of Us Too Belgium. We strongly support PSA screening.