

Oh...life... what are you doing to me?

Arlette van der Kolk, Board Member, Patient Advocacy at the Olijf Patient Organization, talks about her experience with uterine cancer and about her motivation and work for the Organization.

Listen to your body

Arlette's story begins a few years ago.

Arlette: "In the autumn of 2013, the gynecologist stared at the screen for a very long time while inserting an IUD. On the ultrasound, she had seen something that was not supposed to be there. It turned out to be a fibroid. After some doubts and some more physical discomfort, the decision was made for me to have surgery. The fibroid would be removed along with my uterus. At first it seemed that the ovaries, important for hormone balance, could be preserved. After further examination by the pathologist, it turned out that it was not a fibroid, but a very rare, malignant and hormone-sensitive tumor. So the ovaries had to come out after all. And then, at the age of 47, I was suddenly in menopausal transition. Not so much fun. It was stage 1 uterine cancer, so luckily we found out in time."

In the Netherlands, approximately 2,000 women are diagnosed with uterine cancer each year. This makes it the most common cancer of the female genital tract.

"From an early age, I learned to listen carefully to my body. I was never really afraid for a moment. Due to another condition, I had spent a lot of time in hospitals as a child. I learned to ask questions at a young age and that helps with my peace of mind. I am doing well, but many women are not as fortunate. I have no metastases, and I did not have to undergo chemotherapy."

Using my experience for the Olijf Patient Organization

"During a check-up, I came into contact with the oncology nurse at Erasmus MC. She asked me if I wanted to become an ambassador for the Olijf Patient Organization. With my background as a researcher and my biology degree (Radboud University), she said I could make a valuable contribution."

"While I had to think about the ambassadorship for a moment, it did appeal to me. I realized I could use my experiences to make a difference for someone else. In my daily work as a senior researcher at the Labor Inspectorate, I am involved in research, quality and safety and enriching the processes of and integrating knowledge from different target groups. These are skills that come in handy in my role as a board member for a patient advocacy group. My board membership with Olijf will end at the conclusion of this year, but I will remain involved with the organization, as a kind of unpaid policy officer, because the work is far from finished."

"Olijf has roughly 140 volunteers – mostly patients, but also relatives and healthcare professionals – who are committed to the organization in all kinds of areas. They organize local activities, such as themed meetings in hospitals or local centers. They answer questions from patients and ensure contact with other patients, write for our quarterly magazine – Olijfbblad (olive leaf) and manage our website and social media. In addition, they represent patient interests in-hospital and assist in the development of healthcare guidelines.

And Olijf is increasingly involved in scientific research for, for example, the KWF or ZonMw, to contribute ideas from a patient perspective or to assess patient materials."



Arlette van der Kolk

Board Member, Patient Advocacy at the Olijf Patient Organization

New medicines, better techniques and early detection

"During the corona pandemic last year, we received a lot of questions about postponed operations. That was a worrying development. We did directly contact the NVOG (The Dutch Association for Obstetrics and Gynecology), to ensure that attention is paid to this and to be able to inform our members/patients properly. In the coming year, we will continue our participation in research, guidelines & decision aids, development of indicators and many other projects. We keep a close eye on new medical developments, and we are cautiously optimistic. Living a few months longer sounds nice, but at what price? Ultimately, it is about the actual effects on the patient's quality of life. I am convinced that new medicines, better techniques and early detection will ensure that important steps will be taken in the coming years." •