

The thing in my breast

When Andrea Behet palpated her breast at the beginning of 2020, there was this lump. The gynecologist says: Harmless. A year later again: no cause for concern. Then it becomes clear that it is cancer that has continued to grow. A mistake? No, says the doctor's insurance.

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The worst thing, says Andrea Behet, is the feeling of having been betrayed. The 54-year-old from Göttingen has been through a lot in the past three years. She had advanced breast cancer. So advanced that both of her breasts had to be completely removed. She fears for her life, sometimes more, sometimes less. But nothing has bothered her more in recent months than the feeling of having been betrayed by her gynecologist. "It was such a betrayal," she says as soon as she is greeted at her front door.

Andrea Behet, brown knitted sweater, jeans, her red hair tied back with a rubber band, stands in her attic apartment in a residential area of Göttingen on a cool day. She is peeling carrots and potatoes for a vegetable soup, soon her fourteen-year-old son will be coming home from school. Three years ago, the high school teacher was diagnosed with breast cancer. Diagnosed, not discovered. Because Behet had already discovered it herself almost two years earlier. Back then, in early 2020, she noticed a lump in her right breast. She had often felt harmless hardenings that appeared and disappeared again. But this lump remained.

Andrea Behet was all the happier when her gynecologist of many years sent her home again after an examination in April 2020. She said it was just "harmless hardened glandular tissue", says Behet. "I was totally relieved. My son had just turned ten at the time and several relatives had already died of cancer, his grandma, his grandpa, his aunt. He was also worried."

What her son will think of her medical history one day is what worries her. What if the cancer wins? How does she want to be remembered then? Certainly not as a woman who is to blame for her own fate. But that's exactly how her gynecologist portrays her. The gynecologist who failed to diagnose the cancer in her breast. In order to regain control of her own story, Behet recently sued the doctor for malpractice. But the fight is tough. As is almost always the case when patients fight for their rights.

Experts estimate that more than 200,000 people in Germany are victims of medical malpractice every year. But of those who sue at all, only a small proportion get justice. For most, it is an odyssey that often begins when they ask their doctors to hand over their patient file - as was the case with Andrea Behet. Without a complete file, patients have a hard time in court because they can hardly prove incorrect treatment with legal certainty.



A law with which the coalition government wanted to “strengthen the position of patients in the event of treatment errors” was not passed. Otherwise, Andrea Behet would probably have found it easier to assert her rights. But she is already failing at the first hurdle. She has been trying for a year to get a correct patient file from her doctor. Because the doctor, as Behet now knows, had manipulated the file when the cancer was finally diagnosed. This was a year and a half after she remembers the doctor first pointing out the lump in her breast.

After the visit to the doctor in April 2020, Andrea Behet was no longer particularly concerned about the lump. Even though she noticed that it was getting bigger. “I’m the opposite of a hypochondriac,” she says. “If a trustworthy specialist tells me that it’s a

harmless lump, then I'm done with it." She doesn't see her gynecologist again until February 2021. The usual cancer screening is scheduled - breast palpation, cervical smear, ultrasound of the uterus, which has had a benign growth for many years.

According to her recollection, Behet had to actively approach her doctor about the lump in her breast. The doctor reassures her again, Behet tells her. The fibroid in the uterus would have to be monitored further and the lump in the breast was harmless. "We were totally relieved," recalls Behet's partner David Lee, who has now come into the kitchen. He is also a teacher.

She remembers the doctor giving her breasts marks, but nothing happened:

Two months later, in April 2021, Andrea Behet went back to her gynecologist and the cervical smear revealed a few conspicuous cells. The doctor also performed an ultrasound of her breasts, noting "BI-RADS 3" for the right breast and "BI-RADS 2" for the left. Behet still remembers how the doctor explained to her what this meant: "She said: Mrs. Behet, you are a teacher. I give one breast a three and the other a two. And you know, there's nothing to worry about with the grades." David Lee also remembers the grades his partner told him about.

But the lump continues to grow. In the fall of 2021, the tumor in her right breast is so large that it can even be seen from the outside. Behet still trusts her gynecologist. But she wants to have the lump removed as it is bothering her. So she makes an appointment at the Göttingen Breast Center. She remembers how she went there for a mammogram one November morning in 2021 and happily told them that the lump was harmless. But she was immediately called back to the breast center for the afternoon - for a puncture. The doctor who took the tissue sample already told her not to expect a positive result. "I remember planning my funeral on the bus ride home," she says.

The next day it was clear: she had cancer. The tumor in her right breast is now 18 by 17 by 13 cubic millimeters, according to the ultrasound. As it turns out later, it is actually 52 by 21 by 18 cubic millimetres - larger than a pigeon's egg. It turns out that the left breast is also affected. "For a year and a half, I lived under the assumption that the lump was not my enemy. But the opposite was the case."

This is followed by: Surgery, chemotherapy, hormone therapy, radiation. Nausea. Vomiting. Hair loss. "An absolute shit time," says Andrea Behet. She also struggled with her situation. "The opposite of early detection happened to me. But every idiot knows that early detection is everything when it comes to cancer. I just thought: I might die and my child is still young."



She has no idea what lies ahead of her.

When she regains her strength at the beginning of 2024, she wants to understand why her cancer went undetected for so long. She asks her gynecologist for her patient file. On February 15, a Thursday, the assistant hands her a stack of papers at the practice and her partner waits in the café. They want to read the file together. But they can't believe what it says: "Mammography not desired! strongly recommended", it says under the date of April 2021. "My doctor had never mentioned a mammogram because of the lump," says Behet. "Everything was supposedly always fine." They couldn't even drink the coffee anymore, they were so outraged.

On further examination of the file at home, they discovered further inconsistencies. For example, the file did not contain a grade of "3" for the right breast, as the doctor had said in the interview, but "3-4". That is a huge difference: "3" means "probably benign", in which case a re-examination is recommended after six months. 4, on the other hand, means "suspicious" and a biopsy is due. His girlfriend was in a state of emergency for days after seeing the file, says David Lee. "This file read so differently to what Andrea had always said after her visits to the gynecologist. In the files, there was the narrative of the patient being stupid and resistant to counseling."

What do they always say? Cancer is an insidious disease. And that's true. The first tumor cell develops one day from a completely normal body cell, which then continues to multiply, imperceptibly at first. But Andrea Behet found the way her gynecologist treated her even more insidious than cancer. "Anyone can make mistakes," she says. "What offended me was this insincerity, this perfidy. After all, it was her repeated all-clear that made me watch the cancer grow every day for a year and a half."

She found the way the gynecologist treated her almost as insidious as the cancer

The day after looking at the file, a Friday, she wrote to the doctor. No longer “Dear doctor”, but “Dear doctor”, and demands an unaltered file. On Monday, she goes to the practice with her partner and a friend to talk to the doctor in person, with whom she has had a good relationship for years.

Behet and her partner remember a quiet, open conversation in her kitchen, where vegetable soup is simmering on the stove. At the end, the doctor apologizes. This is also written in a memorial protocol that Behet's partner and her friend signed shortly after the visit to the practice. The doctor agreed to delete the note “Mammography not desired! strongly recommended”. She also remembered the palpation findings from April 2020, which were missing from the file, and the ultrasound of the lump in February 2021, which was also missing from the file.

But in the new file that the doctor hands her two days later, these admissions can only be found in part. Under the April 2020 appointment, a handwritten addition reads: “Patient states palpation findings on the right, I remember this.” However, the April 2021 appointment now simply reads in a toned-down version: “Mammography recommended according to my recollection.”

In the meantime, the doctor has changed her account of what happened. She does not want to speak to SZ. Instead, she has called in a media lawyer to speak on her behalf. The lawyer admits that his client only wrote the “3-4” and the entry about the allegedly recommended and unwanted mammogram in the file afterwards - after she had learned of her patient's cancer diagnosis at the Göttingen Breast Center in November 2021. However, he writes that she “always” recommends a mammogram for such findings. The doctor also contradicts Behet's statement that she felt the lump for the first time in April 2020 and viewed it on ultrasound in February 2021. In fact, she called the patient back in two weeks later in February 2021 because of the lump and found no lump at all in April 2020.



But why did she then write in the file in the meantime that she remembered the palpation of the lump in April 2020? This only happened under pressure from Behet and her friends, writes the doctor's liability insurance company, HDI Gerling, in a letter to Behet. Because the conversation had been so confrontational, the doctor had made “various concessions” that “did not reflect her real recollection”. The doctor also did not want to “accuse her patient of telling the truth” in front of her friends.

Andrea Behet finds it incomprehensible that she has to deal with an insurance company and lawyers during her fight against cancer. She recently returned from rehab. There were many women recovering from breast cancer treatment. Only a few had to have more tissue removed, so they were now thinking about having their breasts reconstructed. Very rarely, a whole breast was removed. She was the only one who had two breasts completely removed, she says. “I was the pink elephant, because there was no other woman who had cancer on both sides and had been walking around with it for so long.”

Andrea Behet repeatedly emphasizes that everything happened as she says it did. She even made an affidavit to a notary about the events of April 2020. "I declare this in the knowledge that I am a civil servant. I'll lose my job if it's not true," she says. She considers the doctor's explanations to be outrageous. Why wouldn't she have had a breast examination in February 2021? “It would be completely illogical not to examine the breast of all things at a cancer screening appointment where there is a lump in the breast.” And she would never have refused a mammogram if the doctor had expressed even the slightest doubt that the lump was benign. How often did her son ask: “Mom, could that be cancer?”

Lots of exclamation marks, as if to say, this patient is resistant to advice

Andrea Behet is not only a sports teacher, but also a qualified biologist. She has always been health-conscious, but now she takes even more care of herself. In the morning, she buys cake for her visitors. She only takes a slice herself that a friend has baked. It contains almost no sugar.

But she is not only fighting against the return of the cancer. She is also still fighting for her rights. In the meantime, Behet has discovered further discrepancies in the file, which is available to the SZ. For example, on February 9, 2021, it says that the doctor advised her to have her fibroid surgically removed. But Behet allegedly did not want this. It literally says: “Myoma enucleation/LASH not desired!” and “Information clearly provided”. Again, as with the subsequent entry on mammography, in this strange order: first the patient's refusal, then the alleged recommendation - as if it didn't have to happen the other way around.

“And then there's this stylistically highly questionable exclamation mark,” says Behet. “It's obviously intended to underline the myth of the patient being resistant to advice.” She says that the doctor spoke to her that day about the possibility of surgically

removing the fibroid. “But she explicitly said she wouldn't advise me to have it removed if it wasn't causing any pain or other problems.” In any case, the insurance company uses the entry for its argumentation: it shows “that your attitude towards recommended therapeutic measures is quite critical”, it writes.



Behet's partner finds this “slanderous”.

So what was really in her patient file and when? To this day, Andrea Behet has not received an unaltered version. HDI has informed her that the original file cannot be restored: In consultation with the software company CGM, it had “tried to have a complete reconstruction of the file created in readable form, as you requested, but unfortunately this was not successful”. Apparently, the doctor had not activated the necessary settings on the system. When asked why this was not done, neither the lawyer nor the doctor said anything.

In any case, it is good news for the doctor that the changes to the file can no longer be traced. The Göttingen public prosecutor's office had meanwhile discontinued preliminary proceedings against her on the charge of issuing incorrect health certificates. This accusation “cannot be established with sufficient probability of conviction with the available evidence (...) because no objective evidence is available”, the senior public prosecutor responsible wrote to Andrea Behet. In other words: there is no file in which the changes can be traced. The proceedings were only resumed recently following Behet's complaint.

Katharina Heynemann knows the problem. “It is still the case that many doctors and clinics do not make any subsequent changes to electronically stored patient files visible and the files are therefore not tamper-proof,” says the lawyer, who is sitting in a blue wool dress in an office in Berlin-Mitte. Together with her husband Jörg, she runs a medical law firm here. The right of patients to have doctors hand over their files “immediately and completely” is repeatedly trampled underfoot, she says. An amendment to the law is urgently needed so that the change and storage data must be treated as part of the patient file.

Even if patients are given access to their files, this does not necessarily help them

This observation has also been made by the Federal Government Commissioner for Patients, Stefan Schwartze. Time and again, patient files are “released incompletely or with a delay”, he says. “But there are also cases in which access is completely denied. That is unacceptable.” The legal situation here is “very clear and unambiguous”.

But even if patients are given access to their files, this does not necessarily help them. A treatment error is rarely detected. The Medical Service of the Health Insurance Funds assumes that treatment errors occur in one percent of all hospital treatments, which would be 172,000 cases per year. However, only a fraction of these are reported to the service. Last year, there were 12,438 suspected cases, with only one in four cases confirmed by an expert opinion. According to patient advocate Heynemann, there is a structural problem with doctors acting as experts. “Many of them know each other and show consideration for their colleagues,” she says. “Biased or unsuitable experts are the main reason why patients don't get their rights.”



This is shown by a similar case of a man from Schleswig-Holstein, whose cancer diagnosis was also delayed. In February 2015, his doctor detected a drastically elevated PSA level, which means suspected prostate cancer, but failed to inform the man. According to the file available to the Süddeutsche Zeitung, he called him once and “could not be reached”. There is no indication of a further attempt to contact him in the file.

It was not until four years later, at another appointment in 2019, that the cancer was diagnosed and treatment was started, but it no longer helped. He died in November 2020, with the death certificate stating: “Multi-organ failure, metastatic prostate cancer”. Nevertheless, an expert found that it could not be proven that the urologist's “breach of medical duty of care was the cause of the regrettable subsequent death”. The investigation was closed.

The doctor and her lawyers do not want to see any malpractice in the Behet case either.

The insurance company wrote to Andrea Behet that it was “deniable that a conspicuous lump was already present in April 2020”. Even in April 2021, it was still questionable “whether the carcinoma had already been discovered”. The diagnosis that it was not cancer had been made “lege artis” at that time and was “at least justifiable”, the lawyer writes.

Michael Lux sees things differently. The gynecology professor runs a certified breast center at the St. Vincenz Clinics in Paderborn. According to Andrea Behet's patient records, he believes that a mammogram should have been carried out in April 2020, but even more so in February 2021 and April 2021. “According to the S3 guideline on breast cancer, a suspicious or unclear finding over the age of forty should always be followed by a medical history, clinical examination, mammography and, if necessary, advanced imaging,” he writes in a statement.

Behet was almost fifty when she visited her doctor in April 2020. With courageous diagnostics, metastasis to the lymph nodes could possibly have been prevented, says Lux. The risk of Andrea Behet dying from her cancer in the next ten years could have almost doubled from six to eleven percent due to the late diagnosis.

She was offered compensation for the manipulation of the file, nothing else

The doctor's insurance company offered Behet 3,000 euros as compensation for the manipulation of the file - not for any errors. This made Behet so angry that she is now suing for damages. “I wouldn't have done it at all, everyone makes mistakes, but this shifting of responsibility onto me makes me angry,” she says. That's why she wants to keep fighting. But every time she receives another letter from the insurance company, she has to take a deep breath. “There's usually some kind of insult in there too.”

In one of HDI's letters to Behet, the insurance company noted that Behet was probably only so persistent because, as a Catholic, she obviously has a special relationship with

the subject of guilt. For her, the word “probably has an even greater meaning in the context of her religious affiliation than in other cases”, writes HDI.

When asked, the Group emphasized that it was in no way intended to judge religious beliefs. If the impression was created, the company apologizes. The doctor also sent a lawyer to “expressly apologize” - but only for the manipulation of the patient file. This is “not legally justifiable”, the insurance company admits in a letter to Andrea Behet. But she should not take this personally. There was “no intention to deceive” and it was also “not done with the intention of harming you”.

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