

# Cancer and Cure\*

## In Memoriam Gyöngyi

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I turned forty three days ago, I just had my birthday. I think I know practically everything about my illness. I insisted on this right at the beginning, and I think that doctors have been sticking to this and are not hiding information from me. But I had to fight for it myself.

It took them a while to notice what my problem was, even though I knew. That's why I went to see a doctor. The first doctor did not believe me, so I went to see another one, and a series of others, and by that time it had turned out that there was a major problem and they recommended an abdominal operation. I was feeling very ill. They only told me I had cancer when the results of the biopsy came. Even though I naturally knew it already from the documentation on the very first day. There were four of us in a room, everyone had a similar problem. And they came to congratulate my roommates on how great their operation went, and though they did the biopsy to be sure, everyone was certain that there was nothing wrong. Meanwhile, everyone shunned me, even my own doctor who was a friend. Back then, I hadn't yet been operated on by the professor. And from this, one obviously guesses what's going on. The others got up the second or third day. They were running around, feeling well, and were nagging me that I was letting myself go, that I had too many visitors, why didn't I get up, and so on. So there came the usual spiel from the fellow patients, and I sensed it, as it was obvious, that the way they treated me was different. Even days later, I still had a fever. I got infusions, nothing was right, none of my results were appropriate, I felt wretched, I was unable to eat anything, and by the time they told me what the diagnosis was, a week after the operation, I was already absolutely certain of it.

I have a college degree in health care, and not just any kind but a district nurse's, so at our school, midwifery and pediatrics – if I may put it in such a self-important way – were much stronger than at the medical university. At the medical university, this is nothing but one class out of many, while we were trained to do just this. Earlier, I also went to a baby and infant nursing training school, where the emphasis was also on midwifery and pediatrics, so I learnt this quite well. I have also worked as a district nurse. Then I became a sociologist, and as such, I was researching infant mortality. I was also reading the scientific reviews on gynecology regularly, so I was prepared to follow everything connected to my illness professionally as well. Besides, I consider myself a woman who thinks quite logically. So I knew all that could be acquired by learning, I put two and two together quite logically, and I have always been very sensitive to the forms of communication and metacommunication too, so the pieces of the puzzle fitted together. And perhaps it's not negligible either that after a while, I learnt to pay attention to my body.

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\* The original interview was made by Mária Hoyer in 1997 shortly before the death of the interviewee.

Incidentally, I already had a quite special ability to do so. I had to learn this along with the illness. Today, I can sense before the CT, the ultrasound and everything else that I'm having a new attack of the illness.

That's the way it happened last year and this year too. I had new attacks twice, and both times, I felt it before any modern diagnostic procedure or tumour marker showed it. By the way, I ran into the doctor who had been my medical advisor for a long time, and whom I had trusted very much. It was him who hadn't noticed for months what my problem was. I'd talked to him, but I'd also heard it from here and there, that back at the time, the reason why he had been so tense and nervous was that his wife had had a similar problem. Before that, he had always listened to me, paid attention, but at that time, he was very nervous. I thought that perhaps our relationship had somehow gone sour. But he had been projecting his tenseness on me. He had blamed me for taking my trivial complaints so badly. He had even told me I was hysterical, and that I should visit fewer doctors, and things like that. I kept insisting that I could feel my ovary hurt, so he examined me and told me there was nothing wrong with me. So our relationship had somehow gone sour, though I maintain that it was him who had been careless because of his nervousness, and meanwhile, he had been thinking that I was blowing things up out of proportion, it had been me who was nervous, and he had paid no attention to me.

Actually, the way I was told the diagnosis itself was very civilized. They asked my husband to come in, and when he entered the ward together with the doctors, I knew right away what the deal was, because he's unable to hide these things. I even asked them "what's up, boys, is the biopsy bad?" Then we went inside the room and they told me what the case was, just the way they should. They only told me certain parts of the truth, of course. The fact itself that I had cancer and that I needed treatment. I knew that ovarian cancer was very dangerous from my studies, though back at that time, it was considered so malignant that they regarded it as practically incurable. The survival rate is much better these days. But they hadn't told me what they later wrote on my papers: liver metastasis, and they hadn't told me back then that I was about to undergo the operation I eventually had. They hadn't told me how bad the picture they had found at the operation was, and they hadn't told me what they told me later on, that they themselves believed I had no chance to live for even half a year.

Though I think perhaps they shouldn't have told me. Except there was an accident later on which is perfectly normal in the current health care system here. At one point I was sent in for some checkup and was given all my files, together with the description of the operation I had had, from which – even though it was all in Latin – I naturally understood everything, the liver metastasis and all, so then I asked about all that from the doctor. He gave me evasive answers, and then bawled out the nurse on duty – who was responsible, herself alone, for thirty or forty people who, let's say, got an infusion – in a horrible way. Of course she was unable to walk me upstairs. So there was nobody to blame for this, it was simply the way the hospital hierarchy worked, that whoever was at the bottom was given hell. So that's the way I learnt, from the findings, how serious the problem was. Then I asked the doctors, and from then on I insisted on seeing every finding and having them explained to me.

I think that I have the right to that, as a citizen too, but still, I had to fight for it. And from then on, they acknowledged and respected this. Perhaps from my point of view it was better this way, but I got into such a state of mind about having cancer, and my world view, my view of the future, my perception of my own body has changed so much that still, I'm saying they should not have dumped all that information on me in such a way. They should

not have let this horrible paper get into my hands. Since I got into a complete state of shock because they put liver metastasis on it. I'd been living for half a year thinking I had liver metastasis. And that's a dreadful way to go, because one becomes stinking, disgusting and suffers enormously. Liver metastasis is something absolutely horrifying. Of course, it later turned out that I had no liver metastasis. It's not only that I had none at the time, but I haven't had one since either, and it somehow looks like I'm going to get away with this. The doctor said if there hasn't been one during the two years, it's likely there won't be any. Still, it was a huge shock...

All the time, what I found interesting and what told me that there was something very wrong with me was the fact that the doctors shunned me completely. The ward rounds became a mere formality. It wasn't a proper ward round, they were just standing around and didn't even ask me questions, they didn't dare to address me the same way they addressed the other patients. Of course I kept asking questions, asking what the situation was, how was I, what my prospects were. All the time, my impression was that doctors don't know how to react in cases like this. And it's not simply that it didn't occur to them that the patient, if she's intelligent enough, obviously detects the signals from their dissimulating way of communication, but I'm afraid that they didn't care much either. There are a few doctors who have retained their human sensitivity.

When I went to the Uzsoki hospital for radiotherapy, for example, I met such a doctor there. And my current doctor at the Péterfy [hospital] is also someone who has this sensitivity. But the majority try to avoid it. They are unprepared for it anyway.

Of course, it wasn't easy to force them to tell me everything. It was difficult to convince the oncologist at the clinic to treat me like a partner, but I finally succeeded. I asked him these damn tough questions first. I looked at my files. I peeped into them and kept asking and asking, and he saw that there was no way out: he must explain everything to me. I got to know the rest by telling them that the department where I was at that point used to be my mother-in-law's old department, and the doctor treating me before had been an old friend. So I needed my past as a health care employee, the physicians in my family and my own aggressiveness to ensure that I'm treated like an adult.

I'm trying to educate my fellow patients to be insistent too. Except, if the patient does not have adequate knowledge about her illness, the proper relationship between her and the doctor can hardly develop. Unfortunately, doctors don't speak an everyday language to explain to a patient her illness at her own level, regardless of her education. They think that the patient should adjust to the medical jargon. But that's impossible. I think medical training and further training are to blame for that. They learn everything in Greek and Latin at the university, and by the time they get near a patient, many forget the Hungarian meaning of these words.

I already knew at that time what my problem was, only they didn't believe me. Once the doctor on duty was someone I went to a conference organized by the Fetus Protection Society with. At this conference, I represented the more liberal standpoint, so to speak. When I was admitted to the clinic, this doctor recorded a long case history, and then it came to the question of how many abortions I had had and I told him I had three. I knew I'd blackened myself in his eyes. And that's the way it happened, because he treated me horribly afterwards. He gave me hell for not bringing some age-old final report with me, and he kept harassing me with things like that. So this was an interesting experience. I was unable to communicate with a bunch of doctors at the clinic. Of course, there were exceptions: the oncologist head physician and a few young doctors fresh out of university who knew nothing in general, but were nice.

Here, where I am right now, and at the surgical department, I was able to communicate with everyone. But these worked the way normal hospital departments do, where there are, let's say, ten doctors and everyone knows what the patient's problem is. A clinic doesn't work that way. There are plenty of doctors and plenty of departments, and no one is really in charge of the patients. Even though the healing process is something that requires a good deal of personal contact. It's also shocking that a doctor has the right to judge his patient from a moral standpoint, even though if he intends to cure, he should fundamentally remain neutral. If the doctor's political or professional views are different from the patient's, the patient might end up in a compartment, and because of that, her chances of healing can diminish. And that night, when this doctor was on duty, I had bad luck. Thank god, he had the best nurse with him, who provided me with everything I needed.

By the way, in Hungary, people's lives very much depend on who is on duty that day at the hospital, or whether someone falls ill on Saturday or Sunday or on a weekday. In my case, there were problems with the first chemotherapy too. I had an intravenous implant in such a way that the poison itself was flowing directly into me, spreading inside my body. So it had to be pulled out quickly, inserted elsewhere, the whole thing was very awkward, the best doctors were all away at the countryside at some training, but a good young doctor was on duty, and the nurses were very young, too. And one of the nurses who was to leave at two o'clock stayed in until six because of me. Things like this happen, too.

Perhaps it is already apparent from what I've said so far that I consider properly informing the patients extremely important. In this respect, I find the publications on chemotherapy that is written in the language patients speak and is meant for patients excellent. Except I think that now they've done this, it should be available everywhere. I got hold of it at an event organized by the cancer patients' association, but I haven't seen it in the hands of any other cancer patient yet. Certain hospitals, like the gynecology clinic, have very good general information brochures on childbirth, abortion and a number of other things. Only they've somehow left gynecological oncology out of it...

For example, nobody tells the patient how she should live during chemotherapy. They don't even tell you that you should drink plenty of liquid. And there's not a word about what you should eat and what you shouldn't. That you should eat lightly, for example, or that you shouldn't eat meat. There's no information whatsoever. Nothing! I'm already familiar with all the literature concerning this. There's a bunch of books from which I've picked up all sorts of information. These are published by the Forrás Foundation, the Foundation for Human Beings against Cancer and the Association of Cancer Patients as well. But I don't think that the little old pensioner ladies can afford to buy these, let alone pick out from them, from among the bullshit, what's important and what's good. A book like this would be in great demand. And again, I was able to get hold of these books as a researcher and a participant at these conferences, not as a patient. Even though this would be extremely important. But there's nothing, nothing at all, there's zero information or help! Neither about food, nor about lifestyle! Nothing about things like what to wear instead of a wig, for example, or any kind of practical information like this. It's not certain that health care should be taking care of this, by the way. Rather, civilian organizations should do something about it.

Slowly, I've changed during my illness. My soul, my psyche has changed, and the direction of my attention to the world has changed too. I know that if I was pensioned off, the state of my illness would more or less stabilize, and if I could financially afford it, then what I'd most like to do is to tell what I know, what I have learnt. To strengthen civilian groups with my experience. This is a mental urge. Even now, I get plenty of calls from women with ovarian cancer who ask me to tell them about my experiences, at least over the phone. This

self-help network is sort of working with breast cancer patients, but the reason for that is partly that breast cancer can be cured with good results. But my fellow patients are still dying of ovarian cancer, one after the other. Six of us were at the clinic. Two of us are alive now.

A fellow sufferer can help more with certain things than a doctor or a nurse can, as she has lived through the same thing. If I'm telling the doctor about whatever complaint I have – and it has happened to me too, on innumerable occasions – his answer is that I shouldn't bother about it. And then later it turns out that I should bother. Of course, I understand that it's difficult for the doctor too, since how should he be able to tell who's a hypochondriac. They can't deal with every single complaint, and they don't even know about certain complaints either. Many doctors have inadequate information about patients' suffering, problems, and true complaints. There are plenty of complaints the poor patient is not even thinking about because she thinks they are irrelevant, even though they are symptomatic. If the patient knew about these beforehand, she would not be so scared. I notice these myself, and I ask my mother-in-law who's an internal specialist but through me has learnt quite a bit of gynecological oncology. I dare to ask questions and I can call my doctor at home any time. But the majority of patients are not in such a situation, yet are distressed and have a lot of questions that she forgets when she's alone with the doctor because she's afraid to say even a word.

Or there's the problem of the diet. In many places, it's the cleaning lady who distributes food. And if someone is on chemotherapy, they bring him or her the boiled pasta with cabbage that's made with fat. Even though a number of cancer diets exist. There are ones that are low-fat, contain no red meat, are low in animal protein, rich in fibre, rich in cereals and roughage which are accepted worldwide. They are in the scientific reviews as well, except doctors don't seem to be willing to take notice of this. There are a few nutritionists trying to break free from this. There's one at the orthopedic clinic who's trying to push for this. She's a very deft and bright girl, but she's the nutritionist, so she can't fight the doctors. And the first thing they can save money on is the patients' food, the doctors wrongly think. Even if, besides the fact that a proper diet facilitates healing, the way the patient feels is not a negligible factor either. Nevertheless, they often bring dishes after chemotherapy I'd be sure to throw up, if I ate them. Stew with dumplings and the like. Well, as a relative of a doctor and myself almost a professional, I did avoid these at the Péterfy. Except other people don't have the same advantages, and I think the notion of 'cancer diet' is itself missing from hospital nutritionists' vocabulary. And it's obvious that it does not depend on the nutritionists but on the doctors, their mentality, their attention. If the doctor is not paying enough attention to the patient's mental problems, if they are unable to communicate, it will sooner or later lead to a mutually growing distrust.

It was eventually due to this mutually growing distrust that I went to look for another place. This wasn't an easy decision, as one gets used to the fellow patients, the circumstances, and a sick person adjusts to new circumstances with even greater difficulty than a healthy one does. If I see that the doctor does not believe in my healing, it weakens my own faith too. The physicians in my family have also reinforced me in this decision. So it was a very difficult decision, but still, I left.

Cancer has four states, I would rate myself as being in state number two or three, but it's entirely my own conclusion, and I have no idea whether it's true. Especially in the light of the fact that at first, they indicated on my papers that I had liver metastasis, and that's the end of the final state. These metastases are judged by different standards. Those with a gynecological origin, meaning they are close to the starting point, are called A-metastasis, if I'm right. Those that are further away are B and C. In the case of cancer, the more remote

metastases are the really dangerous ones, when they are scattered all over the body and the process is irreversible. But I have no idea which state I'm actually in because they don't tell the patient about that. They never told me things like what my chances of survival were. I always asked them about this, but they kept avoiding the question saying "it's impossible to tell these days, when there are so many modern medications," and especially because "so many patients, so many cases."

It's telling how difficult it is to erase something that once gets written on a paper. Here's an example. When I was going to the Uzsoki in the spring for radiotherapy, they put on my file that I was in state 3/C. I wondered what 3/C meant. I had no idea that I was a state 3/C patient. And when my husband asked the doctor about it, he told him that wasn't the case at all. Then they discovered that based on my old liver metastasis, someone must have put it there automatically. Yet these are sensitive issues, because patients generally know at least what states exist, it's not only me who knows about them. These states are also known by patients less educated than myself. So it seems totally absurd that while they keep it a secret and do not tell the patient, because of such a banal mistake, the files can end up in her hands and she can learn about a potentially false diagnosis in such a way. This is a completely kafkaesque situation...

Therefore, I think that at medical universities and especially during oncology training and further training, psychology should be given much more room, as doctors themselves do need such training. What's more, even mental hygiene training, since in the end, they are defenseless against these various traumas, too. In this respect, they are unprepared. Because dealing with patients in a serious or fatal condition on a daily basis is an enormous mental strain for the doctor, too. This is such a huge mental burden that doctors also need help with it. Doctors should also be relieved of this horrible tension. They are incapable of handling it – with a few exceptions – no matter how professional they are.

Once I also met the head of the oncology institute's gynecology department at a conference. He's an excellent specialist with up-to-date knowledge of the international scientific literature. He said he had no idea what a psychologist would do at an oncological gynecology department. And yet he and the specialists like him are not the butcher-type gynecologists every woman has met, this is an elite group. And they truly believe that they know so much already... This is the self-assured, patriarchal view that excludes the advocates of other professions that represent a different type of knowledge or of civilian organizations.

In my view, some kind sort of holistic approach is indispensable for curing, which allows one to take a look at the human body and mind together. Unfortunately, this is completely missing from the majority of gynecologists. I think the reason for this is that it's not the most clever and the best prepared doctors that become gynecologists. In general, regarding their overall knowledge of how the human body and mind works, they are unfortunately a very weak and unprepared bunch, with a few exceptions. This is widely known in health care circles, and we could easily prove it if we checked what their results were at university, or if we'd make them pass an IQ test. Most of them don't see any further than their own specialty area. They are only able to concentrate on their own, and professionally, they don't know anything about whatever is outside it, they don't dare to take responsibility for anything, so they close their eyes instead.

There's one more thing that I think deserves to be mentioned. There are few other areas where the male-female relationship is so manifest in the doctor-patient relationship, since ninety percent of gynecologists are still male. I'll tell you my personal experience about the situations women with serious gynecological problems have to face and maybe this will shed some light on why the male doctor-female patient situation is important. Once I was

taken to a hospital, and as there was no room elsewhere, they put me in a six-bed ward among really nice, fifty- to sixty-year-old peasant women. They spoke in a dialect, I was feeling very ill, and they helped me a lot, pampered me, they were very kind. One morning when I was still half asleep and they were talking among themselves, it turned out that at home, they don't support a woman with a tumour because "there's no need for an empty woman." So in villages, it is still a generally accepted view that the woman who is "unpacked" is no longer a woman. So even though the woman who is "unpacked" could have a much less troubled sex life, she's no good. So then her married life ceases, and she gets talked about even at the local pub. There's no need for an empty woman. Not much later I was in the same ward with a younger woman and she told me that she came from a simple family too, and as soon as her mother was "unpacked," her father left home. And I heard this now, in 1996. I even heard that a mayor's wife had cancer and she was bound to have a major operation, but as she was the wife of the highest ranking official, she did not dare to go ahead with it because it would have been such a shame on her husband, so she rather died instead. She died, and the whole village knew that was the reason why she died! Yet she died rather than having herself operated on! This is shocking!

As a sociologist, it's quite something to examine what sort of prejudices are alive in villages, what a woman must face, and the dilemma it all presents to the gynecologist. Because if he is well-meaning, he will be willing to issue a false final report. It's a question, though, whether this can be interpreted as good intention. Or whether he says he doesn't care, it's the patient's own problem, she should solve it, or whether he consults a psychologist on what to do in such a situation. If the region is more backward, gynecologists somehow act differently too. These "empty" women are devalued in their eyes as well. The closer we get to the center, the more this attitude seems to be changing. Moreover, there are appropriate machines for radiotherapy in, let's say, three places in the country, cytostatics and chemotherapy are expensive, they don't even have access to it, and on many occasions, treatment is not done based on someone's needs, what matters is which medication is cheaper. So there are a lot of external circumstances binding doctors' hands. Not to mention whether the woman can physically endure the journeys to the county town for the radiotherapy sessions which she has to attend thirty times. Or is her family able to afford it – there are so many difficulties in the countryside that don't arise in Pest. You just have to check the service centres on the map: how can a woman from the countryside get to a CT or magnetic resonance examination?

And another roommate of mine springs to mind, who complained that though she had had a big operation in a countryside hospital, she kept bleeding afterwards, which is bad, and that the doctor dispatched her in a really rude and arrogant way. He prescribed some medication for her and her condition did not improve. Yet the doctor is in a difficult situation too, he can't handle it because he hasn't got the tools, the equipment, and he shoves his tension, his helplessness back on the patient. And the poor woman keeps on suffering, and her problem does not get treated.

If health care is in such a wretched situation, they should at least change the way they inform patients, that doesn't require such a large amount of money. It would have helped me a lot earlier on if there had been someone near me who had already been through the same illness. This was working well on a small scale, as the patients who were also at the hospital but in a more advanced state and who have already been through a lot told me how it was going to be, how it wouldn't hurt, how it would hurt but I shouldn't be afraid of it, how this and that would happen. I needed very much to see a civilian patient who was in good shape, whose hair had already grown back and who was working, and was in the state

I had been in last year or the year before for six months – so that I could see that it was worth it. I missed this a lot. We don't think about this. The attention to provide such help is missing. I know that this works much better in Western Europe. Unfortunately, self-motivated, civilian helpers are not even allowed into most hospitals here. Yet the goal of these self-help groups is exactly to share their own experiences, so that the patient can see the end of the tunnel. Unfortunately, what the professional press calls patriarchal healing very much still stands, especially in the field of gynecology. When the doctor thinks he knows everything, or rather he's the one who knows everything the patient needs, and the patient shouldn't argue too much. I've heard from a number of places that these civilian organizations had placed posters at the oncology institute that were taken off, torn down. Horrible things happen there. There was a newspaper called Napforduló, it was a nice, quality paper, four issues had been published earlier. I hear that they've got money to come out again. I hope they'll manage to.

*Translated by Ágnes Csonka*