

Positive thinking is essential. This was stressed once more during a recent national initiative in Belgium around cancer fundraising and awareness, called 'Kom op tegen Kanker' (act against cancer). It is important to stay positive, even if this means taking a leap of faith.

Professor Frederic Amant (Catholic University of Leuven, Belgium) and the Polish cancer patient Monika Tomczuk chose to jump in the deep end, despite an impossible diagnosis. She had a child after chemotherapy during her pregnancy. Their story.

BY NATHALIE CARPENTIER PHOTOS STEPHAN VANFLETEREN

Patient Monika Tomczuk: 'That child saved my life'

My first child I lost due to preterm labor. During my second pregnancy, I had to go to my gynecologist for a check-up every month, as a precaution. That one time, the routine check lasted longer than usual. Too long, I thought. When they wanted to take a biopsy, I was sure: something was wrong. I had a lump on my cervix. It was malignant. My uterus would have to be taken out. My child as well. I was three months pregnant.

My First thoughts were: "I am dying". In Poland, cancer is as much as a synonym for death.

That day, I cried on end. Hugo, my husband, proposed to have the fetus removed. We would go on a trip. Take a breather. Slowly begin to think of a new kind of life. Different than what we planned for, but a good life as well.

Then I knew: no way. I don't want a trip, I want my child. I picked myself up, resolved not to cry anymore and to fight a hundred percent for this. When we went to the specialist team in Leuven, we had to convince them. Initially, they also wanted to terminate the pregnancy, since the lump turned out much bigger than they had thought. But I refused the operation, I wanted to keep my child.

Why? Before the check-up with my gynecologist, I didn't even know I was sick. I didn't have a single complaint. Had I not been pregnant, I wouldn't have known I had cancer. Because of the life in my belly, they discovered the tumor that early on. In a sense, that child saved my life.

I thought: you have to live. If we have to, we will wait until I am 28 weeks pregnant and the child is viable, I said. Then you can cut away anything you like, first my baby will be born. Because I was so headstrong, the doctors went to search for alternatives. They collaborated and then informed us of the options. Either have chemotherapy during the pregnancy, or wait until the baby would



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be viable. This meant four months of waiting, which could be too long in my case. Those doctors went through a lot of trouble to find all the available information, even calling to the United States for inquiries. They found out there had been a few babies born after chemotherapy, who were doing well. They were however, very young still – six years old at most. This is what they could tell me, but they could not give me any guarantees. Not that my child would be healthy, not that it would all work out. It could very well be that the chemotherapy would not work for me. That the tumor would not shrink. Then what? Before, I also associated the word 'chemotherapy' with death. Whomever got that, would die anyhow. Then, you are told you will get chemotherapy yourself, whilst carrying this little being within your body. And we both had to live? Very odd the feelings you have at that time. You are afraid of dying, but there is life within you which you want to save.

Call it an instinct, I cannot describe it any other way. The glass can be half empty or half full. I chose half full. You could worry constantly about the child being sick or handicapped. My husband did. He had much more trouble letting go of those negative thoughts. I reasoned differently. Two perfectly healthy people can also bring a sick child to this world. You can always have bad fortune. I thought: my child will be healthy. I knew that.

Those four months, everything revolved around my child, not my illness. The situation appeared quite simple to me. Either I lived, or I'd die. It even went as far as me thinking about who could be a mother to my child, should the lump not shrink by the chemotherapy. I was that determined. For a split second I considered giving up. After the second time I received chemotherapy, when I heard I would not be able to go home for four months. Something snapped. I wasn't prepared for that, and so far from home. That night, the doctor who was on call, came by

and said: 'come on, let's go watch a movie. She took me to the other end of the hospital, to the room of the gynecologist and rubbed gel on my belly. When I saw my child moving for the first time, I regained courage. You have to believe in something. Often, it is in little things.

When we went to take a walk outside, after our first visit to Leuven, I saw a baby's pacifier lying on the ground. At a moment where I was consumed with doubt as to what I should do, I suddenly found this thing. I don't think it was coincidental. This might be a sign that I will come to need that one day, I thought. I picked it up and held on to it for five months.

"Positive thinking, that's what it is about. I was never like that before, though. As a student, when I'd have an exam and didn't know my subject matter so well, I'd be convinced I'd fail. When I had the flu, I'd be whining. Even a dumb hang-over made me act as if the entire world was coming to an end. This is how miserable I'd feel.

I'm not sure I would have had the same strength if I would not have been pregnant, but merely sick. All I did in these four months was for him. Every time I had to eat after the chemotherapy, I had to force myself. Even if I could hardly get anything down, I couldn't throw up. I had to keep eating, keep drinking. For him.

For my mother, I hid the fact that I had cancer. She thought I was in the hospital because my first pregnancy had gone so wrong. Then she started asking questions during her visit. Why there were so few pregnant women on my ward. No room in the Obstetrics department, I attempted. And why were there so many bold people, she asked. Then I couldn't hide it any longer.

I didn't want to tell her because she was already in a difficult enough position. I weighed my words explaining it to her. You cannot compare the hospitals in Poland with the ones here. One and the same word has a whole other meaning there. In Poland, they have to close down hospitals. Sometimes, they cannot even offer chemotherapy. I didn't want her to be constantly scared that I would die. I wanted to solve my problem by myself.

I focussed on the growth of my baby. It was waiting, counting down every day. Everything was checked constantly. On days when I was too weak, I didn't get chemotherapy. They wanted to be safe. At the same time, I saw my child grow. From three hundred grams, to six hundred grams, to eight hundred grams.

Once we reached the beacon of one kilo, it all became real.

One day, Professor Amant came to tell me the lump had become so small, it was hardly detectable on the scan. The chemotherapy had done its work. The child was viable after 28 weeks, but we then decided to wait a month longer. Until Victor would be able to breathe independently. That was a relief. Other patients often said: you are so strong, because of you I forget I am ill myself.

One time I have been very scared: the night before the operation. I wanted to get away, I was that scared. They were going to let me sleep for eight hours, so they would be able to remove my uterus directly following the cesarean section. Would I wake up after that? Would my baby be healthy at birth? Once again, my lucky charm brought solace. During the operation, I was to wear long support stockings. I put the

pacifier all the way in the bottom. When I woke up from the anaesthetic, for a moment I really wondered if I was still on this earth. Your son has ten fingers and ten toes, said a nurse. I didn't get it. Of course he had ten fingers and ten toes. As did I. What was so special about that? It wasn't for a while, until I realized: he is healthy. All is well. It took a few more days before I was allowed to see Victor. I was much too sick. Was in so very much pain. Right after the delivery, they did show me a photo of him. It was a shock seeing him in the incubator. He was so different. He seemed so much smaller than on the picture.

I could hold him for a little while, but it was not at all the way I imagined it. As if it wasn't real. In any case, not the way it was supposed to be. It is very different to delivering you baby and getting it put on your chest. I didn't know my own child. But come to think of it, the entire past period had been anything but normal.

After the operation, all was not yet over. They had to check whether the tumor had not spread. This meant again ten days of waiting and being afraid. But my body was clean. I was, so to speak, healthy. The doctors then admitted that in the four months, they had not been sure as to how my body would react to all the medication. This was why they wanted to keep me in the hospital. So that they would be able to intervene immediately, should I have gone into labor, or anything.

It wasn't until the doctor told me Victor was a bit smaller than expected, but otherwise healthy and breathing well, that my fear subsided for the most part. Though I held my breath for sudden infant death syndrome. The first months I often went to see if Victor was still breathing – holding a pocket light, in the middle of the night. He is now three years old, but I don't follow everything he does with a magnifying glass. If you ask me, Victor is perfectly healthy.

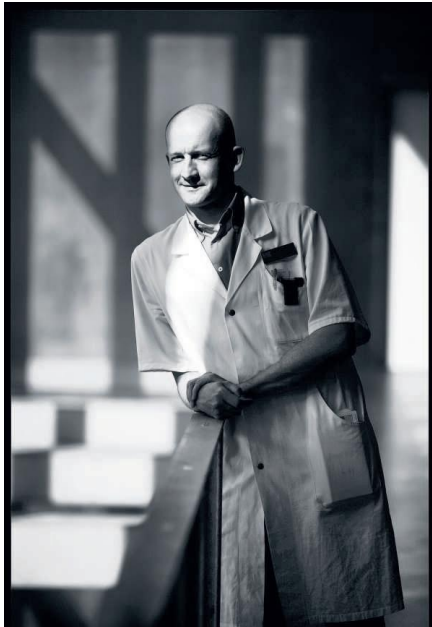
Not everyone understands what I did. When my cousin heard the whole story, she was angry. Asked me if I realized the risk I took? And all because I wanted to walk behind a buggy. Maybe I have been selfish. I so much wanted a child. This was my last chance. Amazing how a tiny creature of three months old, whom you don't even know yet, can determine your life. I had to give Victor a chance.

Many questions came to me only afterwards. What if I had died? How would his father have raised him by himself? All those things, I had never thought about in the hospital. Because I didn't allow those thoughts before. I believe you have to follow your gut feeling. And then I knew it would be all right.

I never thought I could be so strong, so optimistic. This did change me. I have become more strict for others, when they fuss about trivial things. I used to be a real blabbermouth and a rascal. I lost some of that playfulness. Have become more serious. Sometimes, I close myself off.

I am now still stressed around the time of a periodic check-up. The fear strikes again: what if they find something? Every time I need to go for such an exam, I take the pacifier out of the drawer again. That needs to come along. Of course I know it won't change my faith, but still. (laughing) You know, after that first pacifier, I found another five at least. If that means anything, I'm not sure. I am not able to have any more children. She looks at her husband cheekily. Unless you have something to tell me, Hugo?

Gynecological Oncologist Frederic Amant: 'This is about the fundamentals of life'



Someone recently said: a pregnant woman isn't even allowed to take an aspirin, and you say she can have chemotherapy? How is that possible?

Cancer patients seldomly ask us to deviate from the standard. Most chose the treatment with the best chance for recovery. Not this patient. She had cervical cancer, was fourteen weeks pregnant and explicitly asked to keep the baby. The standard would mean to remove the uterus, but in her case, this also meant the end of her pregnancy.

An unusual dilemma, also for us. What did we know? That the tumor was large enough to be life-threatening. But also, that this was a very precious pregnancy. She was still very young, twenty-eight, and had already been through a pregnancy which ended badly. She was now faced yet again with a large threat for her child's life. Only this time, it was for her own life as well.

She was aware that what we proposed offered her the best chances of survival and that there was very little experience with any possible alternatives. Nevertheless, she asked us to give it our all to find another solution. She was willing to do anything to carry that pregnancy to term. This was her specific wish. She was even prepared to take risks for herself.

Standard protocols exist for a reason. Simply because they are usually the best. But sometimes there is a good reason to dare view things in another light. This was such a situation. This was her last chance. She wanted a child so very much. One is obliged to consider the request purely objectively, but you cannot rule out your own

Emotions. If you have four children yourself, you can identify with such a question. Even if you are willing to consider it, as a doctor, you have to take into account first and foremost how safe these alternatives are. You can only come to a decision once you have all the information and are aware of all the risks. Waiting four months, until the baby had grown to term, was not possible. That would be too long.

Chemotherapy seemed the best option, but this choice was not evident. For me neither. Someone recently said: a pregnant woman isn't even allowed to take an aspirin, and you say she can have chemotherapy? How is that possible? She was right. That combined with such frail life indeed seems very contrary. You cannot do this and cannot do that when you are pregnant. And then a medication which is most destructive, much more than a painkiller, that is acceptable? This enormous contrast has made for doctors to deem it impossible for a long time. Including myself. Several of my colleagues have advised us against it initially. But this was mostly due to not knowing and not having the experience. Unknown is unloved. If you are not sure about the outcome, you will usually air on the safe side. In this case, terminating the pregnancy. We went through all the scientific literature on the subject. That was the only frame of reference to depend on. We found that, despite the seeming uncompromising adversity, it was still possible. Globally, only four cases had been described comparable to that of our patient. And then a few on other tumor types. What do you take into consideration? The health of the child and the mother? The children born after chemo, could not be discerned from other neonates. Short term, they were doing very well.

Crucial is that you start treatment only after all fetal organs have formed. Our questions on long-term effects, like memory, school results or cognitive and motor development, remained unanswered. This is why we started a research study at the University Hospitals of Leuven, in order to follow the children.

As far as the mother is concerned, we knew that cervical cancer can be treated by chemotherapy. We told her: the tumor is sensitive to chemotherapy and it is likely your child is not sensitive to it. It is not for sure, but likely. She wanted to go ahead. You then find yourself at a crossroad. On the one hand is a very motivated patient, and on the other scientific data which predicted little issues for both mother and child. This persuaded us. With that data, we were able to reach a consensus. It was an exceptional situation, but nothing suggested we were playing with fire. Naturally, you do have second thoughts. You wonder what happens if it turns out wrong for the mother, or the child? You do feel responsible, even if you are not forget you are dealing with cancer. This makes it an uncertain situation, since cancer can always come back.

Say the illness does relapse, then is this because of the alternative treatment or due to an aggressive cancer? You'll never be sure. Once a decision is taken, you cannot be tempted to hold off because of insecurity. You cannot hesitate. This would compromise

the mothers' chances. To counter all unknown elements, we hospitalized her for a long time. We didn't want to take any risks. Even if all looked well, you never have any security, merely a 'highly likely'. Looking back at it, it all seems simple: you administer chemotherapy. As if you kick off something and see it through just like that. Going for it, does not mean you can never question your initial stand. If the tumor would have grown anyhow, we would have been forced to terminate the pregnancy after all. We kept that into consideration. At all times, it remained a 'wait and see'.

She was extremely strong. For her, everything evolved around the life of her baby. She was prepared to accept all side effects, because she knew it was for the greater good. Once you are at that stage, your attitude changes, I think.

Life comes in a package. You can't say yes to chemo and no to the nausea. She knew this. A normal pregnant woman worries about innocent, often trivial complaints. Her perspective was entirely different. When you know your life is at stake, your level of worrying about things shifts. If you have a back ache in those circumstances, you put this into perspective. She knew very well there was much more involved here. That is was about life or death. All normal questions, such as whether she would have her baby at home, or by c-section, what the delivery would be like, escaped her. They were irrelevant. From the beginning it was determined; as soon as the baby would be viable, she would have a cesarian section and be operated on. The question marks vanished. The delivery would be unknown to her. When having a cesarian section, normally you are given an epidural anaesthesia, so that you can witness the birth consciously. In her case, she was under general anaesthesia.

That operation was a very big step. She went under with a fetus and with cancer, hoping to wake up with a live and healthy child and without the tumor. All signals had been reassuring during her pregnancy: the echo graphic exams showed a normal growth and health of the fetus. She herself didn't have more side effects of the chemo than others, and the tumor became smaller. For me, the health of the child remained the biggest insecurity.

The birth was very suspenseful. When the pediatricians then say the child is doing well, a weight is lifted off your shoulders. When you realize four months before, you had considered terminating the pregnancy, and you then see the mother and baby together, you know you've made the right decision. It is a tremendous reward. You feel happy that you dared to reconsider the protocol this once.

Even then, the questions don't disappear. You still want to know whether the child is doing well after three years, and after seven years. At the time of the birth, you cannot tell if the child will be able to talk normally. Where the mother is concerned, you wonder if the illness will return.

Now, three years later, he had positive test results. She is also still doing very well. We can now look back at this as one of the success stories which other patients can rely on as well. That chemotherapy during pregnancy is without risks, I would

not dare say. However, out of everything we know at this point, it appears to be quite safe.

Since then, we have treated several women with various tumors. Some want no risks whatsoever. To them, the pregnancy is secondary. Others consider: if it turns out negative for her, then at least our love will live on in our baby. When the prognosis is very bad for the mother, you more often see that the child gets priority. But you cannot have the prognosis be worsened for the mother by giving her alternative treatment.

Because there are so many questions on the long-term effects, we are now following twenty-six children carefully, in a study. This includes children who weren't born in Leuven. When we call the parents, they usually respond very relieved. We have been wondering about whether he walks normal, they say – or whether or not his hearing might have been damaged from the chemotherapy. One mother told us her child sometimes has anxiety attacks. She recognized herself in this during the time she received chemotherapy. When she saw herself having poison administered into her body whilst carrying a child. She couldn't wait coming to Leuven for the follow up study. We were able to reassure her. Nothing was abnormal in her child.

I am a gynecologist by education, but I deliberately made the switch to gynecological oncology. When I was confronted with a life-threatening illness in a patient, I realized my involvement is much larger with cancer patients, than it is with pregnant patients without any major issues. It is for them that I want to fight. This is about the fundamentals of life, whereas a pregnancy in itself is a natural process.

Obstetrics also deal with the essence of life, but with gynecological oncology, you are at a cross road between life and death. Oncology has changed my perspective on life. It is too precious to fuss about the small stuff, the futilities. You have to accept every day as a gift. There are many people at our age diagnosed with a life-threatening cancer. Yesterday, they were as healthy as you and I and then suddenly that thundercloud in a clear sky.

I turned forty last week and told a patient that I was having trouble with the aging process. I ought to be ashamed, she threw me in the face. Why was I complaining? Many people would give money to be able to reach that age. You then realize again what it is really all about.