

Breast cancer at 28, recurrence within 4 months... “If you were going to die soon, how would you want to live?” My three rules of looking forward in life.

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"No breasts, no hair, no appetite. I have nothing." (From Koko Isabel's book, "To You Who Have Been Diagnosed with Cancer")

Koko, 37, was diagnosed with stage 2 breast cancer nine years ago at the age of 28. She immediately underwent surgery, but the cancer returned within four months. Her entire right breast was removed and her hair fell out due to anticancer drug treatments. For the first time, she became aware of the possibility of dying.

However, Koko wrote about her own experiences in her book, "To Those Who Have Been Diagnosed with Cancer". This book holds the subtitle;

"Three Rules for Looking Forward"

Why did she decide on these three rules while undergoing treatment for cancer?

It is said that one in nine women will develop cancer. I interviewed Ms. Koko in advance of World Cancer Day (February 4th).

Suddenly diagnosed with cancer: The day I broke down in tears in front of my parents

Koko was 28 years old when she was diagnosed with breast cancer. Let's hear the circumstances leading up to her diagnosis.

—*First, please tell us the events leading up to your diagnosis.*

After graduating from university, I worked at a financial institution and was busy every day. I had decided to go to the UK for work, so I was preparing for my trip.

While I was taking a bath, I was concerned about a pimple that had formed on my chest. I touched it and noticed a lump. I was going to leave Japan soon but I thought I should have a check-up for peace of mind and booked one.

—*So you were diagnosed with breast cancer at that check-up?*

Yes. The only illness I had had before that was the flu. I had never thought that I would be diagnosed with cancer. I had no idea what they meant when they told me that my cancer was malignant.

I asked the doctor, "Does malignant mean 'cancer'?" The doctor nodded his head with a serious look on his face.

—*Do you remember how you felt at that time?*

My first thought was, "Oh, I can't go to London". After that, my mind went blank and I didn't know how to tell anyone.

I couldn't sort out my feelings, and decided to call my boss. As soon as I said, "I have breast cancer," the tears started to stream down my face.

My boss said, "I understand the situation. Don't worry; we'll make sure you can focus on your treatment in Japan."

Thanks to his quick response, I was able to take medical treatment while taking leave from work.

—*How did you inform your parents?*

I told my mother in advance that I was going for a regular check-up. My mother was standing in the kitchen when I returned to my parent's house and she casually asked me, "Oh, by the way, how was the results from your check-up?"

I said, "It was...no..." I told her in tears, "I have breast cancer." I remember my mother was terribly upset and my two younger sisters were also upset. My father was a very quiet man and listened to me in silence.

The next morning, before going to work, he said to me, "Don't worry about the money; just concentrate on your treatment".

I think my father considered what he could do all night. He didn't say much, but what he did say was very reassuring.

—*How did you proceed with the treatment after that?*

My first examination was at a private breast clinic, so I was then referred to St. Marianna University Hospital. I also had a second opinion at the Cancer Institute Hospital. I was told at all three hospitals that my cancer was malignant, and that I had no choice but to accept the diagnosis of 'cancer'.

In June 2013, two months after I was diagnosed with cancer, I underwent surgery to remove a part of my right breast. Since I was only 28 years old at the time, I was also guided through the egg-freezing option and underwent four courses of egg-freezing operations before undergoing the anticancer drug treatment.

At the time, I was just trying to keep up with the fast-paced situation. My only motivation was the belief that if I endured this now, I will soon be able to get back to my old life.

Recurrence of cancer within 4 months. I looked like a 'defective' person after having my right breast removed.

—*When did you find out that the cancer had returned?*

I was scheduled to start anticancer treatments at the end of October after my egg freezing procedure but I once again noticed a lump in my right breast.

It was a recurrence only four months after the surgery.

—*How did you feel when you found out about the recurrence?*

It was very unusual to have a recurrence within four months. I remember my doctor was very surprised. He said, "I think there is no choice but to have a total right mastectomy. I want to operate as soon as possible. You can get a second opinion, but I don't want to waste time."

That was the first time I thought, "Oh, I might be in trouble... I'm going to die."

At first, I was too scared to confide in my family. I remember that my best friend, to whom I had confided everything, came to pick me up that day.

—*Were you immediately convinced to have a total right mastectomy?*

No, I wanted to keep my breast if possible, so I also went for a second opinion. But although I was young the cancer had progressed quickly and had recurred within 4 months.... I finally had to accept it. It was in October that I underwent a total right mastectomy. It was six months after the initial cancer discovery.

After the surgery, I hated taking a bath... There is a mirror in my bathroom and my reflection made me look like a 'defective product'. Losing my breast was a huge shock to me as a woman.

My mother was concerned about my condition and asked me, "Would you like me to put a cloth over the mirror?" I replied, "You don't have to do that", but it was hard until I got used to seeing it.

I underwent reconstructive surgery the summer after the surgery. Of course, it was totally different from my previous breast and I had scars from the surgery. It was not natural anymore but the fullness had come back. I can now go to the spa and hide my breast and you would never know. The reconstruction was a great for my self-esteem.

No breasts, no hair, no appetite. The things I realized when I hit rock bottom

—*Did you undergo anticancer treatment after the mastectomy?*

Yes, I did. I received eight rounds of anticancer treatment. After the infusion of anticancer drugs, I felt so bad that I couldn't even stand up for the first week. I felt a little better in the second week, and again in the third week.

I experienced a whole series of side effects from the anticancer drugs: hair loss, feeling so bad I couldn't eat, weight loss, edema, constipation, mouth ulcers, anaemia, fatigue, and so on.

When I was in pain, I was always asking myself, "Why...? Why did I let this happen to me?"

—*In your book you describe yourself as being at 'rock bottom'.*

Yes. That's right. I couldn't see the future at all.

—*What was your 'light' in the midst of your difficult situation?*

I still remember it clearly. When I was taking a shower once I suddenly thought, "Maybe I don't have to cure cancer anymore. Maybe my cancer will never be cured."

I thought, "If I only have one year left to live, how do I want to live it?"

At that time I was living my life thinking, "I am unhappy because I have cancer. But it is only natural that I have to endure such hard times." But I absolutely did not want to live unhappily. I was so disgusted that I began to cry while taking a shower.

I wanted to live my limited life happily, even if it was short. I want to enjoy life. So, let's start being happy now.

The change in my feelings that day was so vivid that I still remember it clearly. It was like an 'inspiration' or 'light' that as only visible because I had hit rock bottom.

— *What changes have you seen since that day?*

Instead of 'enduring' the anticancer drug treatments every day I began to consider how I could 'enjoy' things from the third week when I began to feel better.

I had no breasts, no hair, no appetite... but I had *time*.

During the weeks that I felt good, I learned a new dance, got a health-related certification, took leisurely walks with my best friend, and spent lots of time alone with my mother. It was the first time since I was three years old when my sister was born that I had had my mother all to myself.

I went to the places I wanted to go and explored new cities. I travelled a lot.

There were days when I wore a wig and partied in clubs without telling my doctor (laughs). Only then was I was able to be a 'normal girl' who didn't have to worry about the people around her.

— *So, do you believe you can change the way you look at life just by changing your point of view – even if the situation around you doesn't change?*

Yes, that's right. There were many things I couldn't change at the time but I realized that there was one thing I could definitely change – my point of view.

Whether the situation is good or bad, it is up to me to decide whether I should deem it 'good' or 'bad'. Instead of waiting for a good situation, I decided to enjoy my life to the fullest *now*, even if I am undergoing painful treatment! This decision made a big difference in my life.

— *I see that this idea leads you to the "Three Rules for Looking Forward". Please tell us these again.*

The first is to turn a bad situation into a positive one.

The second is to make the most of what you have.

The third is to look around and realize that you are blessed.

Cool 'bald pictures' are still my compass for life

— *What challenges did you try after setting the three rules?*

When my hair fell out due to the anticancer drugs, it didn't fall out evenly I was temporarily in a very miserable situation. I decided to go bald and asked my best friend to shave my hair with clippers. At the time, all my photos were of me in my pyjamas looking in pain.

I suddenly mentioned to my sisters, "If I'm going to go through the trouble, I'd like to leave a cool and beautiful bald picture of myself."

Then my sisters called their acquaintances and arranged a studio and makeup artist. They asked me in detail what kind of image I wanted to capture; what kind of props I wanted to use, and so on.

The baldness photo shoot with my sisters is truly a wonderful memory.

—*I was attracted by the dignified beauty of the photo.*

It is a picture that captures my strong will to turn a difficult situation into a positive one.

I think it is the picture in which I shine the brightest.

I still have this photo on display in my room. I look at it whenever I feel like I'm losing sight of what is important. It is like a compass and a reminder of my life.

I am living a 'dream of a dream' now.

— *The third rule was to 'look around you.' Listening to you talk like this, I feel that the generous support you received from your sister, your family, your best friends, your boss, and the others around you also helped you in your fight against the disease.*

I think you are right. I can't thank the people around me enough for their support. My best friend from junior high school was with me through the whole process of my treatment.

When I was on the anticancer drugs he always took the train to my house to see me. When I wasn't feeling well she would gently watch over me, and when I started to feel a little better, she would ask me, "Would you like to try some of this?" In the third week, she thought of ways to have fun together. She was with me every step of my life... the times spent with her back then was truly a beautiful one sent from God.

My family also celebrated every time I got through a certain treatment with a cake and small gifts. They would say, "You did your best, well done!" It was only a small gesture but those 'celebrations' gave me so much strength.

The list of side effects from anticancer drugs is very long. Thanks to the people around me, my list of 'good side effects' was just as long.

— *I love the words 'good side effects'.*

Yeah... it was a really big good side effect.

When I was in a difficult situation, everyone supported me as much as they could without saying anything. People around me showed me the most important things in life with love.

I often wonder if I will ever have a better experience in my life.

The treatment was hard and I lost a lot of things, but I also gained a lot more.

— *What is your life like now that you have overcome the disease?*

I am still receiving treatment via oral medication but my body has gotten used to it now and I rarely have any side effects. It has been 8 years since my last surgery - thanks to everyone I have passed the five-year mark! My annual check-ups have been uneventful so far.

— *How is your work going?*

Fortunately, I was able to return to my old job, and now I am studying corporate compliance at Fordham Law School in New York, where I was given the opportunity to study abroad.

Of course, it's not all fun and games, the studies are tough, I get overwhelmed by the strong people around me, and I get homesick...

But from where I was in the dark 8 years ago saying, "I have no breasts, no hair, no appetite, I have nothing", I think I am now living in a 'dream of a dream'.

I got here thanks to those around me who supported me at that time. I fought for it myself, too.

I want to continue to live my life looking forward without losing sight of the essence of life.

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Editor's note

"Don't wait for the right situation to come along; be happy now."

Koko's rule in life is something that will gently push us all forward. Even if we are not in the same situation as her we are all living through the Covid-19 pandemic where it isn't always easy to foresee what will happen tomorrow.

What cancer taught her has become her very attitude toward life itself. Her dignified beauty left a lasting impression on me during this interview.