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INDEPENDENT, OBJECTIVE AND EVIDENCE-BASED

Interview: Preventing bowel cancer

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My life has changed quite a bit since getting bowel cancer six years ago. I was 45 years old when it was diagnosed. But I am no longer angry about my illness. I feel I am stronger and have more energy today than I ever had before. Being confronted with my own mortality was a shock at first, but ultimately also a very beneficial experience.

Had I known about preventive measures back then, things may not have gone as far as they did. My grandmother died of bowel cancer when she was 64, my mother when she was 52 and my aunt when she was 37. It was pretty obvious that bowel cancer ran in our family. But nobody told us about the associated risks. And if I hadn't fallen ill myself, who knows what would have happened to my daughter or my sister. I for one knew nothing at all about preventive measures.

One morning I woke up and wanted to go to work as usual. But then I suddenly started bleeding heavily. I got scared and drove to the doctor's. Two days later I was already in the hospital and didn't know whether I would ever be able to go home again.

Because I had seen so many people in my family die of bowel cancer, when I heard my diagnosis I thought I would only have a few weeks to live. At first it was inconceivable to me that I had a chance of surviving. I had the incredible fortune of being treated by very good doctors.

Just before falling ill I went on holiday. I had a wonderful time and never felt better. I would never have thought that I could get cancer. I didn't notice anything was wrong at all. I had no pains, no weight loss and no problems with my digestion. If the tumor hadn't started bleeding I doubt I would have noticed anything until much later.

When I got out of hospital I felt like I had to do something. I couldn't just sit around and feel helpless, like I just had to wait and see whether it turns out OK or not. I went to the library and took out all the books on bowel cancer, to inform myself and read a bit about it. This is how I found out about a clinic that does tests to see if your bowel cancer is hereditary. I had the test done, a family tree was put together and it was determined that I had HNPCC (hereditary non-polyposis colorectal cancer).

During my time at a health resort following my hospital

stay I realized that I had to do more. I couldn't just settle for the fact that the cancer had been removed and that everything had been taken care of. I wanted to make sure that the cancer wouldn't return. It was through the health resort treatment that I came into contact with my doctor. That was the best thing that could have happened to me.

Once a year I have an endoscopy of the bowel. It doesn't hurt at all. It's really no big deal. There's no need to be afraid of having one done.

I do a lot of sport and eat healthy. I make sure that I do things that are fun and make me happy. I have joined a very nice gym. If I work out for two hours and then go to the sauna and Jacuzzi in the spa area, I notice how good it is for both my body and mind. I now do that three times a week. Quality of life is very important to me.

Over the last five years I have only had one cold, last year, and nothing else. My immune system is very good. I think I'm doing so well because I do all these things.

I also try to surround myself with things that do me good. After I left hospital back then I went to an animal shelter and took a dog home with me. I had always wanted a dog. He's the best therapist I could ever wish for. If I'm feeling down I take him on a walk through the woods and fields. I take my music along too, and then I feel better.

The genetic predisposition is still the worst part of the illness for me. I love my daughter more than anything. I can't stand the thought that I could have passed on the defective gene to her. In five years my daughter will have to start having annual check-ups too. But I still don't really know whether she has the defective gene.

I tried to talk to my daughter about it back then, because it could have big implications for her future if she has inherited the predisposition. It could affect her choice of partner or decision about whether to have children. Had I known about it back then, I would have decided not to have children. I am very happy to have my daughter and I love her more than anything else, but had I known back then . . . My daughter doesn't want to find out whether she has the gene or not. I can understand her decision, but on the other hand it could turn out that she doesn't have it. As things stand now, she always has to live with the uncertainty. It's a very sensitive subject. My sister said right away that she wanted to know.

I now accompany my sister when she has her endoscopy

done. She experienced the same as I did in our family and has to go for an endoscopy once a year. After all, bowel cancer is relatively easy to treat if found early on.

Nowadays I want to live my life the way that is best for me. That doesn't mean that I am inconsiderate to my family and friends, but I experience my life more consciously and intensely. I try not to plan my life around the future, but live in the present, for today. I no longer make long-term plans. That was very different in the past. I'm actually quite happy with my life. It would be great if things stayed as they are.

ACKNOWLEDGEMENT

These real-life stories were gathered during interviews with patients who generously shared their experiences with us. We are very grateful to these interview partners.

All of them have given their permission for these stories to be published here.

The opinions and comments in these stories are the opinions of individuals. They are not necessarily shared by IQWiG and are not intended to serve as recommendations to help people make decisions.

Glossary

colorectal cancer

Colorectal cancer is cancer in the large bowel (including the colon) and/or the rectum. “Colo” stands for the colon, and “rectal” for the rectum. Colorectal cancer is one of the most common forms of cancer.

immune system

The immune system is the body’s defense system and its task is to protect the body against germs or degenerated cells (like cancer cells). The immune system is very complex and has not been understood in every detail yet. There are two components: the cellular immune defense (for example “scavenger cells” and “killer cells”) and the complement system (“antibodies”, for example).

diagnosis

The term diagnosis (from the Greek word *diagnosi*: “distinguishing”) is used to mean the identification and naming of an illness or a disease. A diagnosis is usually made by evaluating the medical history, symptoms and test results. The tests include both comprehensive physical examination and blood tests or examinations using medical instruments such as ultrasound or x-ray.

Sources

The German Institute for Quality and Efficiency in Health Care (IQWiG)

The German Institute for Quality and Efficiency in Health Care (IQWiG) was established by legislation to provide evaluations of the effectiveness, quality and efficiency of healthcare services. This includes the assessment of medicines as well as the publication of health information for consumers and patients.

Evidence basis of our health information

Our information is based primarily on systematic reviews of the effects of health care. Systematic reviews are necessary to gain an objective picture of health care. In order to do this, a clear question is formulated. Researchers then find all the relevant studies that could answer this question. They then evaluate those studies.

You can find a list of the evidence and other scientific literature on which this information is based at [**www.informedhealthonline.org**](http://www.informedhealthonline.org)

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