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INDEPENDENT, OBJECTIVE AND EVIDENCE-BASED

Interview: Preventing bowel cancer

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I have had ulcerative colitis, a chronic inflammatory bowel disease, for 28 years now. My risk of getting bowel cancer increases every year because the whole of my large intestine is affected.

At first I didn't want to have to think about it. I was young when I was diagnosed with ulcerative colitis. There were plenty of things I preferred to think about rather than serious illnesses and bowel cancer. I just never thought about it. For years I pushed the subject aside.

I only started thinking about it when, after many years, a doctor suggested I should consider having the whole of my large intestine removed. Then I understood that I couldn't carry on ignoring the subject. Ever since then I have had regular endoscopies of the bowel – once a year for the last 15 years. It wasn't always easy at first. My first experiences were very unpleasant.

I had my first endoscopy of the bowel around 30 years ago. I was, of course, very scared of the procedure and results because my symptoms were relatively serious. I was afraid that they would find bowel cancer. Around that time I had been losing a lot of blood, had 20-23 bouts of diarrhea per day and had lost a lot of weight. I was worried that I had bowel cancer and about the procedure. I can still remember the room it took place in although it was such a long time ago. My memories of that procedure are very unpleasant.

Over the last 15 years, however, the endoscopic procedure has changed drastically. There is no reason to be afraid of it now, as long as the doctor is experienced and understanding. I don't even notice the actual examination itself. I find it important to talk to the doctor beforehand. It helps to know who is doing the endoscopy and the surroundings. But I don't feel anything during the procedure and have no pain. I'm not at all afraid of it anymore.

I was very lucky to find a very good doctor in my hometown. I've been going to him for about 12 years now. I trust him and am confident that he does the endoscopies thoroughly. He has had a lot of experience with the illness, is very open, and I am sure that he does his job very well. I feel I can be very honest with him and that I can talk about the examination results with him. It's very important to me that I have the possibility of discussing the results and any

further steps a few hours after the endoscopy, when the anesthetic has worn off, rather than straight after it.

I have talked to my doctor about this a lot. It helps me to know that he is thorough during the examination.

Although I have had the illness for decades now, I only recently realized that warning signs of bowel cancer can be recognized very early on if you have regular endoscopies.

I take anti-inflammatory medication to fight the inflammation caused by the ulcerative colitis. Maybe these drugs also reduce my risk of bowel cancer.

If I feel that my illness is getting worse, that is if my symptoms such as blood in the stool, diarrhea and pain increase, I react immediately. As a result, in recent years I haven't had any serious bouts that required stationary treatment. I used to wait far too long before seeking medical help and starting treatment.

Leading a healthy lifestyle is also very important to me. I hope that it will help to prevent cancer from developing. I go jogging several times a week and try to eat healthy. My aim is to achieve a general sense of well-being.

I often wonder whether I am doing enough or whether there are other things I should be doing. It's not always easy. When my daughter was still small, there were often times when I was scared of having bowel cancer and it being diagnosed too late. I used to lie awake at night and worry about it. Quite a few tears were shed. I would ask myself whether I was handling things properly and how I could cope with the fear. It was a really difficult time for me. But that was long ago. One thing is for sure: finding out and chatting about it during the many talks with my doctor gave me a feeling of security. To cope with the situation I just needed someone who knew what they were talking about and who I could talk openly. Talking to others who are in a similar situation also helps tremendously.

In my opinion it is very important not to stick your head in the sand and instead face the possibility of bowel cancer. You can't assume that other people will take care of everything for you. You have to overcome your fears and get informed, so that you feel that you are doing all you can and don't risk having any regrets later.

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

inflammation

An inflammation is a (defense) reaction of the body to an injury, irritation or infection. More blood is brought to the respective body part to protect the body. This is why this body part feels warmer, becomes swollen and red and is usually more sensitive. If the inflammation affects the mucous membranes, they secrete more fluid than usual. This helps to wash out the germs that have entered.

ulcerative colitis

Ulcerative colitis is one of two similar forms of chronic inflammatory disease of the bowel (the other is Crohn's disease). Ulcerative colitis affects the large bowel. There are periods without symptoms, but also phases of pain in the left abdomen, diarrhoea and weight loss that may be so severe that people cannot go to work or even need to go to the hospital.

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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