



*'Coen Völker offers us a book of great value for all people with cancer.
He gives us a map of how we can face our fears.'*

— Hiske van Ravesteijn, MD PhD, psychiatrist and mindfulness trainer

Fear of Cancer

A 5-step program to
live with uncertainty
and fear of recurrence

Coen Völker

Lannoo

For

Noud de Haas

&

Gerard Jansen (1937-2019)
— who loved my mum deeply

*Recognise fear – but don't let
it destroy your love of life.*

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Foreword

Coen Völker offers us a book of great value for all people confronted with cancer. He offers us a map of how we can face our fears. This book is written for those who face anxiety and fear in relationship to cancer. Meeting cancer in your life can be a great threat. All that seemed secure might have become insecure. Both the experience of the body and the mind can be totally disrupted. Fear is a very human and common reaction to such a threat, but feeling fear and being anxious can still be shameful experiences. However, all of us will sooner or later be confronted with fear. The current worldwide outbreak of COVID-19 shows that none of us is exempt from being at risk for illness and probably none of us is completely without anxiety.

While working in the field of psycho-oncology, I have met many people with fear for cancer recurrence. This fear can be overwhelming and paralyzing. One of the first clients I met was Bob, who was very anxious. He could hardly get out of bed in the morning and his mood was very low. His mind seemed completely occupied by fear for the future. There was no space left to enjoy the current moment, nor for truly being in contact with his family. Bob and his wife were both desperate and asked for help. Step by step he learned to recognise and acknowledge his fear while saying “*Ah, so this is*

what fear feels like”. He learned he could also choose to focus his attention on other aspects of his experience, instead of obsessing on fear. Bob started to plan activities and walked a lot. Whether he was anxious or not, he would try to stick to his plan of activities. His sense of agency – the feeling that in one way or another one can handle the situation, however difficult it is – started to grow. Bob and his wife told me that they felt more connected even though the risk for cancer recurrence was still there. Not all people with cancer experience fear as intensely as Bob, but almost all know what it is to be anxious. *This is what fear feels like.*

We do not have to eliminate fear. We can learn to stand close to it. This book shows us how we can stand close to fear and be kind to ourselves at the same time. Coen Völker has developed a model to assist those who are being overwhelmed by fear. The acronym RITTA can remind us of what we can do when feeling anxious. This book is an invitation to experiment with different ways of relating to anxiety.

*There is freedom waiting for you
on the breezes of the sky and you ask:
“What if I fall?”
Oh but my darling, what if you fly?*

— Erin Hanson —

December 2019 I sent Christmas cards to friends and family with the famous words of the Australian poet Erin Hanson (2014): “*What if I fall? Oh but my darling, what if you fly?*” Coen appreciated these words. He asked me to use them for the foreword as he recognised this process in his

clients. After being treated with cancer, after leaving the hospital, there often is the fear to fall again. And falling *can* happen. However, life might become much better *if we dare to fly again*.

Hiske van Ravesteijn, MD PhD, psychiatrist and
mindfulness trainer, 25 *May* 2020

INTRODUCTION: Why This Book?

Fear of cancer, fear of cancer recurrence and fear of cancer progression is a major concern for people who have had the diagnosis of cancer turn their lives upside down. More than 85% of patients with cancer report fear of cancer recurrence – even if they have a good prognosis, even when the doctors tell them not to worry. This fear can last for many years after the last medical treatment and doesn't just go away in time. Sometimes it gets stronger *after* medical treatment (especially with young people) and years later it can even spike just as high as during medical treatment. For at least one in three patients this fear becomes a severe problem. Over the last 20 years I have seen many people struggle with fear and anxiety. Many people understand that it's normal to be afraid when you get treatment for cancer, but very few people truly understand the impact that fear has on the lives of patients and their families. And even fewer know what you can actually do about it.

My hope with this book is that readers will find support, helpful information, guidance, clarity and hope so you can have fruitful dialogues and supportive conversations on the topic of fear of cancer, fear of cancer recurrence or fear that the cancer will become unstable and spread. Basically, it's the fear that things will get worse or that recovery will fail.

This book is specifically for patients and families who deal with fear, anxiety or stress. It's both for people who have a good prognosis and those who know that their illness cannot be cured. Sometimes I will describe some of my clients in an anonymous way. Like Penny.

Penny is a 48-year-old bus driver who was successfully treated for breast cancer 7 years ago. She dropped out of work declaring she couldn't work any longer since her mind was driving her crazy. The routes that she was driving as a bus driver were so familiar to her that she could, more or less, drive them on autopilot. This gave her mind a lot of space to think. And she kept thinking about the possibility that her cancer would come back and ruin her life. The trigger was that her best friend's cancer returned 8 months before and, ever since, Penny had more difficulty sleeping and she became more tired.

Many of my patients have fear and anxiety about the future, just like Penny. When patients are interviewed years after their treatment, *fear of cancer recurrence* is one of their most unmet needs. Many wished they had gotten more tools on how to cope with stress and fear. Doctors, nurses, counsellors and psychologists are being trained on how to support the patients, but the interviews suggest we have a long way to go. Research of Belinda Thewes and colleagues (2014) also shows that 40% of psycho-social staff and clinical staff have great difficulties in recognising and helping patients with their fear of recurrence, but my own impression is that this percentage is actually much higher. Fear of cancer recurrence also tends to be higher if patients are not satisfied with how medical information is being communicated.

Some patients want *more* information about their disease while others find they get overwhelmed by too much or too detailed information. Professionals need to tune in with the patients, and patients need to communicate their needs so their fears stay manageable. Different people want different things. So it is important to talk about medical communication and how well it is received.

When people receive the diagnosis of cancer, many feel they have stepped onto a rollercoaster with tests, treatments and lots of waiting times. And after medical treatment, they need to pick up their life again, which can be difficult. For many, cancer is a life-changing event that can put tremendous stress on oneself and one's family. This is very common and normal. Many people get a lot of social support during those times. But after treatment, social support can dry out a bit and the patients themselves really want to get on with their life and their jobs. Some people do get on with their lives pretty well but, according to international studies, 50-85% still report medium to high fear of cancer recurrence and 7-10% have severe anxiety that really needs clinical treatment from a therapist.

These numbers are roughly the same all over the world – in the Netherlands, Canada, Australia and the UK. And for around 30 to 50%, fear becomes a *chronic concern* that doesn't lower in time. Time alone is not a healer. And many of my clients feel shame that they can't lose their fears. Fear of cancer is present independent of treatment, prognosis, education or gender. So people with a bad prognosis or little education experience the same amount of fear as people with a good prognosis or with much education. Both men

and women have fear. It seems we're all the same. Although it does seem that young women are especially vulnerable to suffer from fear. And when people still have a great deal of physical symptoms, like pain from surgery, then this can also trigger daily fears. Research from the Radboud Medical Centre in Nijmegen (the Netherlands) found that one in three patients who have a good medical prognosis have severe fear of cancer recurrence. But they also found the same number in partners: one in three. So fear is not only common for patients but also for partners.

Your mind might have many “what-if’s”

Many of my clients feel embarrassed about their fear or say they used to be positive and now seem to have a negative or pessimistic mind, full of doubt. You might feel like you can't get used to the uncertainty of the future and your mind might have many “what-if’s”. *What if my cancer comes back? What if they can't treat it anymore? What if I don't want treatment? What if I can't bear treatment? What if this tiredness and fatigue won't go away? What if I can't keep my job? What if my sexuality won't come back? What if I can't control my feelings or get depressed? What if I stay a cry-baby forever? What if I'm too late to notice a recurrence? What if my children can't cope with a recurrence? What if... I will die?* I want you to know that all these “what-if’s” are very common. Many people, like you, suffer from anxiety and fear after cancer. Not because you are not strong. Not because you are pessimistic. But because you are human. And humans have both the blessing and the curse to be able to think into the future and ponder upon the past. But like one of my