

Anke van Haften

There is no such thing
as good cancer!



zorgindruk

A true story about thyroid cancer
based on experience

de Graaff

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A JOURNEY OF STRENGTH AND RECOVERY

Prior to the European Thyroid Association congress in Santiago de Compostela in 2014, patients who had been diagnosed with thyroid cancer embarked on a pilgrimage along the famous *camino* to Santiago. This pilgrimage, following in the wake of the pilgrims visiting the shrine of St. James, made a deep impression, not only on the patients themselves, but also on us as physicians and on the people of Santiago. A pilgrimage to Santiago is symbolic of a road paved with suffering, full of confrontations with yourself and your environment, but also one in which you come together with others and come into contact with the true meaning of your life.

In this book *There is no such thing as good cancer!* Anke van Haften describes her journey from the diagnosis of thyroid cancer to her life as it is now. A journey that is comparable to that of her fellow sufferers on the way to Santiago. Her story is an open and confrontational account of a journey full of doubt and concern, but also a journey of strength and recovery.

Thyroid cancer is regarded by some people, surprisingly enough including doctors, as a good form of cancer, because the life expectancy of patients with thyroid cancer is generally good. The fact that this view entirely overlooks the profound experience of a patient who is diagnosed with cancer, regrettably requires a rebuttal.

The book therefore not only offers great comfort to all patients with thyroid cancer, but should also be required reading for all physicians who still have the concept of 'good cancer' in their vocabulary and actually for anyone who is concerned about the people around them.

Prof Dr J.W.A. (Jan) Smit, internist-endocrinologist
Head of the Department of Internal Medicine at Radboud
University Medical Center of Nijmegen

LIFE AFTER CANCER IS A VICTORY!

The burdensome treatment is over and you are happy to be cured! You can pick up life where you left off and you would think that this would be easy. Yet, in practice, this is often disappointing and you realise that the battle is not yet over. Nothing seems as obvious as it did before. How can you fulfil your role as parent, partner, colleague and/or friend again with full confidence and pleasure? How do you restore your confidence in your body again and how do you banish the nagging doubts from your head? You would like to be ‘the old you’ again.

Because of early detection and new treatment possibilities more cancer patients are being cured. This is certainly the case for people with thyroid cancer. Much research has been done in recent years from which it appears that recovery after cancer is a difficult challenge for many patients. This applies to all types of cancer, irrespective of the prognosis. Fortunately, an increasing number of aftercare possibilities exist nowadays on a physical, psychological and social level. Until now, these have only been investigated and applied to a limited extent in people with thyroid cancer. It remains a challenge to anticipate the specific difficulties which may arise at any given moment and to detect these at an early stage. Drawing up a customised treatment plan perfectly attuned to the needs of the individual patient also remains a challenge. We’re not there yet, but if we continue listening to and collaborating with each other; we can be stronger as physicians, care providers and patients.

I always say you will not succeed in becoming ‘the old you’ but ‘the new you’, the stronger you, the you that not only overcame cancer, but also the you who wishes to live a worthwhile life.

Dr R. (Romana) Netea-Maier, internist-endocrinologist
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ORIGINAL TITLE

Goede kanker bestaat niet!

Een realistisch ervaringsverhaal over schildklierkanker

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A true story about thyroid cancer based on experience

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For my three men



Who I love very much. Mum

FOREWORD

I am honoured to be permitted to write a foreword to this book. I have always taken pleasure in reading Anke's blogs on our website, *schildklier.nl* (thyroid.nl). That pleasure is a duality, because the stories are sometimes profound and gripping. Writing about being ill and everything that accompanies that is not trivial. Your life, your partner, your family, your work, your friends, misery about medication and operations, dealing with doctors and so on. How uncertain you become when your body and your health let you down.

Writing is also a release: 'I just want to LIVE', Anke cries out, and so lets us share her feelings and sometimes despair. Anke has mastered the art of captivating us through her writing and has a clear mission. She wants to show how you will go through trying times after being diagnosed with cancer, but that you can pick yourself up again and enjoy life. And in doing this, she helps her fellow sufferers.

For a year, Anke published weekly blogs on the website of our patient organisation SON (*Schildklier Organisatie Nederland* (Dutch Thyroid Association)). Her blogs gradually made an impression on me. How is it possible for her, after being confronted with thyroid cancer, to write so optimistically, humorously and fascinatingly about her daily life? Gradually, I was drawn into her life, her thoughts and the course of her illness. Everyday things become special when you have cancer. An evening of dancing followed by a day of recovery. Cleaning up Christmas decorations, with all the thoughts that this induces.

Anke is active in SON. She is part of a fantastic team of volunteers. A team that provides information, that supports fellow sufferers and that is committed to research and improving quality of life. In 2013, Anke collaborated on the book *Faces of thyroid cancer* and she fired the starting pistol for the *Thyroid Cancer Awareness Run*. These are important

activities Increase awareness of the early diagnosis of thyroid cancer, treatment and care. In this way, the formulation of guidelines by experts and further research on optimal treatment methods for thyroid cancer is promoted.

That action remains necessary, should be clear. There is much to be improved in the field of thyroid cancer care. In 2014, SON ran a survey among patients with the main question: What do you need? What information is lacking? From that survey it appears that there is still a lot of misunderstanding and patients are not adequately prepared for the period following surgery. You're in for a big disappointment if you think that after your operation to have your thyroid gland removed you can simply and cheerfully get on with life by taking a pill a day. Nothing could be further from the truth. The residual symptoms are serious. And that is the great thing about this book. In a personal way, you will be introduced to that world after surgery. Consoling and encouraging.

Thyroid cancer is a form of cancer that is referred to as 'good cancer'. A travesty when you become so ill and you hear someone say this. Actually an insult as well. Cancer is not good, even if it is treatable, as is the case with thyroid cancer. It turns your life upside down and in most cases you can never revert to being the old you. After all, your thyroid is no longer functional, with all the consequences this brings. But there is also optimism. You learn to deal with the residual symptoms, you adapt and tackle life again. How? For the answer read Anke's stories or our blogs at schildklier.nl.

SON hopes that this book will be a source of inspiration. Not only for patients and their families, but also for healthcare providers. Whether being a general practitioner, internist, psychologist or physiotherapist: let the stories capture your imagination. Let them also provide encour-

agement to call on SON if necessary. There is so much information and help available.

Money is always needed for research and information. SON supports this. If you want to contribute to better thyroid care you can donate via schildklier.nl

Thank you very much on behalf of the patients.

Rietje Meijer

Director of the Dutch Thyroid Association (SON)

AND THEN THERE WAS THE C-WORD

There are days when you hardly realise what is happening to you. Like the proverbial 'bolt from the blue', the C-word suddenly became a factor on 26 April 2012...

I have not yet progressed to the point where I can articulate it out loud – writing is easier. The weird thing is that I still feel so little about it. Maybe I should say it a hundred times: 'I have cancer!' Thyroid cancer.

No. Even repeating it 100 times does not work. It still needs time to sink in. My main concern is my children, my husband. As for me, I don't dwell on it at all. I have the positive attitude that everything will turn out alright. By nature I'm inclined to go against the grain and this makes me even more combative than I already am.

I'm not afraid; worried perhaps, but not afraid. I won't let it get me down. I still want to do so much. And this is one of the more treatable forms. I'm told that living without a thyroid is not so bad. I'm going to take it day by day: *Carpe Diem!* Seize the day!

Positive

We have told the boys. They take it well, or so it seems. But experience shows that we have to keep an eye on the boys; you never know with teenagers.

All four of us are positive. I think that this has always been how our family operates. The glass is half full!

Humour

I must say that we naturally all have a good sense of humour. For instance, one of the children asked: 'Mum, will you go bald now?' 'Well, I don't know', I said. 'But you know: hair is hair, it always grows back and if it doesn't I'll shave it off anyway!'

My husband, who is bald, said: 'Don't worry. We can hang out together at a nineties rave party! Two old ravers!' At the time I didn't know that you don't go bald from radioactive iodine.

There is a lot of history preceding this humour. I sing – that is my passion. All of a sudden I noticed that I could no longer sing: I was hoarse and by mid-2011 I had developed a sizeable lump in my neck. A biopsy was done. This showed a benign tumour, two centimetres by three centimetres large. I could rest assured.

Initially the advice from the endocrinologist and the GP was to leave the lump alone, because an operation would cause far more damage than the tumour itself.

Shortly after that, I had trouble breathing. It appeared that the lump was pressing on my trachea in addition to my vocal chords. In consultation with the surgeon the right side of my thyroid gland was removed in April 2012. Actually, I was just relieved. Soon I would be able to sing again.

Diagnosis

Two weeks later, I unsuspectingly went back to the surgeon to have the wound checked, or so I thought. The doctor looked at me and said very quietly: 'Against all expectation we have found a follicular variant of papillary carcinoma.'

I looked at him blankly, or so I think, because he explained: 'You have thyroid cancer.' It is as if the room stood still. For a while there was silence. Next to me, I could hear my husband swallow, but personally I felt nothing at all. It never crossed my mind that this might have been one of the possibilities. Soon after that we left in silence. The doctors first wanted to consider the best treatment option for my specific case and in two weeks' time we would hear what they had decided.

HEAD IN THE SAND

Why me? Why not me?

I go from one extreme to the other... One moment I think, 'Everything will turn out alright' and I am 'Miss Positive' and the next moment I think, 'Who am I trying to fool?' This must be because I'm sleeping so badly; it is making me feel exhausted and I'm irritable.

I'm still very positive though, that's for sure. I mean: I realize that I am ill and that it is not going to be easy, but I'm certainly not going to die!

I notice that I'm getting a bit angry, but that is so futile. Asking the question, 'Why me, why now?' makes no sense! You could just as easily ask, 'Why not me?'

Patience

The big day where the oncologists, the surgeon and endocrinologist gather around the table to discuss what they are going to do with me is an absurd day. It's about me, but I'm not even there.

To make it even more ridiculous, I still have to wait for days to hear what they have decided. This is not for me. I want to be in charge and have control. And don't I have something to say? If there's something I don't have, it is patience!

But in any event I will just have to wait, so patience it is.

Gathering information

After a period of burying my head in the sand, I decide to start reading up on the course of thyroid cancer. My way of thinking was wrong. I thought that there would just be a brief rough patch that I would have to go through.

I was sadly mistaken. As I understand it, I will be burdened with this for the rest of my life, which is something with which I must reconcile myself. I am a realistic person and I want to know what I can expect.

I was shocked by the stories about 'the gulp'. The gulp is radioactive iodine that is administered in a special room, where you are cut off from the outside world for a few days. It sounds like a jail cell.

That is one of the pitfalls of the Internet. All the stories you read there – they can lift you up, but also break you down. But I must regard it as preparation. Experience is the best teacher.

Facing the facts

I must try to put everything that I have read out of my mind for a moment. The silly thing is that I still think: 'This is not about me.' I read the following sentence on the thyroid forum and it is as if I am reading about myself:

Sometimes I have the feeling that I am not participating, but that I am observing. Do you understand that? I don't see this as a burden. I see what is happening and I deal with it. I go through it without a second thought. It sounds daft, but I feel very comfortable with that. No stress!

This is how I see it too, but after reading more of this story I realise that, regrettably, this is a transient feeling and that you ultimately have to face up to the facts.

YOU HAVE CANCER, BUT WE ARE DOING NOTHING

And eventually the waiting is over. Today I will hear what they are going to do!

After remaining positive for two weeks, despite the words: 'You have thyroid cancer', my emotions have come to the fore this afternoon. They told me precisely what I feared the most: 'Madam, you have cancer, but (for now) we are not going to do anything.'

As with the nodule (lump) the previous year, when I was also told: 'We are going to leave it alone' and 'We are going to monitor it with a regular ultrasound check.' To me, this does not feel good. I have something in my body – however microscopically small – that does not belong there.

I don't want to go on with the constant uncertainty and anticipation of how things will develop. I want to get rid of it!

Wait and see

The very well-meaning 'It grows very slowly' is not reassuring me at the moment. They said the same about my previous ultrasound and biopsy: 'What's there is benign.' As it turned out, that was not the case.

To me, it feels as if I am waiting to become ill or waiting for another lump. Does that also mean waiting until the cancer spreads? How can I be sure that my lymph nodes and lungs are clear?

The response to the question of whether a scan could provide more clarity is, 'You won't see anything on the scan because it is too small.' But surely that also applies to an ultrasound?

Questions and uncertainty

I have not been well for one and a half to two years now: constipation so severe that I was even blocked up for one and a half months on one occasion, terribly tired and showed inexplicable episodes of fever.

The lump for which I consulted the doctor in August had been there for some time, but I only made an appointment after I became hoarse.

How long has this been going on? And in the meantime I have the feeling that I was overreacting and not being taken seriously. I still have so many questions and uncertainties. Something is starting to become clear and is dominating my thoughts: This doesn't feel good! It is clear that, according to the doctors, there is no hurry and that certainly provides some reassurance. But that 'something' remains there, is particularly disconcerting.

Mixed feelings

All positivity is gone right now. I'm working to find a balance between common sense, realistic thinking, what the doctor means, my feelings, uncertainty and restlessness. What terrible mixed feelings.

Some people say: 'You should be happy! No surgery and no treatment.' Happy? Happy is nowhere near the realm of my feelings. It doesn't feel good at all. Fortunately, most people react the same way I do. That mitigates the doubt I feel about myself.

New consultation

Three separate, tiny spots of follicular variant papillary thyroid cancer are found. All smaller than 1 cm, but the doctors cannot guarantee that they are not located elsewhere as well.

Soon there will be another consultation with the oncology team, the surgeon, the endocrinologists and the radiologist about possible radioactive iodine (RAI) treatment, because they still have reservations about the treatment of my particular case. The next day, the surgeon will contact me again. I anxiously anticipate the day, but I know deep down that my feelings are right!

I am fighting for myself, against something that does not belong in my body!

‘GOOD’ CANCER

Sometimes, you are dumbstruck by the nonsense that people can come up with. Is it out of stupidity, ignorance or simply because they don't know how to express themselves when it comes to a disease like cancer?

Blunders

With the diagnosis of thyroid cancer still ringing in my ears, an acquaintance of mine informed me without batting an eyelid that for this type of cancer it is only a word, and that it is actually nothing to worry about. After all, I wouldn't die from it. Now, that is a bit crude from a clinical perspective, shall we say.

Indeed, this form of cancer has an average survival rate of 90% over ten years. But he forgot to mention that quite a few people have ongoing problems with residual symptoms, caused by the lack of a thyroid gland. And then I am overlooking the fear of the cancer returning which is experienced by a lot of people, to say nothing about the other 10%. But no, it is nothing to worry about...

I tell myself that it is well-meant, but I'm still left with an uneasy feeling. 'Luckily you have good cancer', still echoes around in my head. Good cancer? Does it really exist?

The second well-intentioned blunder was made by another acquaintance. He told me about a friend who also had this type of cancer but quickly recovered from it. However, eight years later she developed breast cancer and died from it. The moment he had said it, he changed colour three times. 'Uhh, but I must say the two instances are unrelated. I've got an appointment to go to. Have a great day, bye!' It was a good thing that I had a positive attitude then. I walked on with a broad smile on my face. What ignorance.

Denial

And still it doesn't sink in. It still isn't about me. There is still a gulf between me and that disease. It's not that I don't want to accept it, but it simply hasn't sunk in yet. Often, I'm suddenly struck by the thought, 'I have cancer!'

It's in my head as soon as I get up in the morning and when I go to bed at night. But I haven't actually said it out loud, I still see it as being distant. It is also so silly. For example, I dare not put it on my Facebook page. Not because I don't want to flaunt it, but because I simply don't dare to. Afraid of rejection, because people might think you are looking for attention, or afraid of pity or just the fear of having to face up to it.

Singing is more than a passion

Sooner or later I will have to face it. For the time being, it feels good for me to be able to write on a forum. A select group that read this and do not pass judgement. That's how I get more of a handle on it.

Now that I'm back at work, I am basically burying my head even deeper in the sand. I am picking up on my normal life again: making plans and so on. In any case, things are going reasonably well now. Tomorrow I will sing again. As long as I can, I'll keep singing! Singing is more than a passion. It's who I am!

WAITING TAKES A LONG TIME

A blessing and a curse

The wait until June for more clarity takes forever. In the meantime, I dedicate myself entirely to a forum on which I was active before being diagnosed with thyroid cancer. It appears to be both a blessing and a curse. I lose myself completely in the anonymity where I can write as a form of catharsis, but I neglect the most important thing around me: my family. I don't realize it.

To me, after having written everything down, it feels as if there is no longer any substance to it, as if I have rid myself of it. What I unintentionally overlooked is that it must have been terribly frustrating for my family. They are also burdened with questions and feelings that they cannot share with me simply because I am not sharing anything. In their eyes, I share it with 'strangers'. I slowly come to the realization that they are right. This has to change!

The Sea

We decide to spend the time we have to wait positively. There are a few very nice things on the horizon. To get away from all the stress and to take the edge off waiting, the four of us go to the beach in Scheveningen. A breath of fresh air. It works, and wow, what a difference it makes! That day it seems like we're on top of the world. There is no cancer, there is only the wind, with the sea, two croquettes on a roll and a handful of shells.

Sitting in the sand, I watch my two carefree and cheerful teenagers run around like two exuberant young pups that have been set free. We climb to the top of the pier, with my husband and children leading the way. I reach the top a little later because I don't have the energy. When I reach the top, I feel two warm, safe arms embrace me. I feel intensely happy. The sea has washed the cancer away for the day.



Ugly children

Before the word cancer raised its ugly head, our children took part in a casting for the film *The Ugly Children's Club*.

Filming took place in January and the premiere was scheduled for the beginning of June. Not just any premiere, but one in style at the Royal Theatre Carré in Amsterdam. Being on the red carpet with all the tabloids at the ready was quite a sensation, but having a drink and taking your picture with Joep Sertons (Dutch actor) was even more exciting – especially if you are a fan.

I have always been proud of my two lads, but on that day I was undoubtedly the proudest mother in the universe. Even if I think that all the mums and dads on the red carpet felt the same. I can at least say with great pride: 'I have two very beautiful ugly children.'

Judgement day

The sensation of the red carpet glamour also fades. On the day that I am finally going to get more clarity, I walk through the familiar revolving door of the hospital. No red carpet in sight and then I feel it ... finally I feel something. Nerves, the realization, fear. I squeeze my husband's hand. We're going to fight it together. It almost feels like a relief.

PROFIT AND LOSS

I have just returned from the hospital, where I've had a very good conversation with the endocrinologist. This doctor is and will remain my treating physician, the person whom I ask questions and who determines the future treatment plan.

I have been given an extensive information pack. They have just drawn it up, just like the personal supervision by a nursing consultant during the entire process. Excellent! Now I know who my point of contact is for questions and problems I encounter.

They lay out the entire process. Which is to say: the operation with complete resection, then treatment with radioactive iodine and then an extensive scan. After that, medication (thyroid hormone levothyroxine) for the rest of my life and regular check-ups, and the resultant consequences. A lot of attention is also being given to the associated psychological and practical burden. We just take the plunge and get on with it.

I am very concerned about my beloved husband. He is under tremendous stress and I know that he is afraid that I am going to die after all. Maybe not now, but that the cancer will come back. We must really try to put that out of our minds. I would like to reassure him, but it is difficult.

Matter of perspective?

I'm really at the end of my tether. I do the things I have to do, like working and keeping house, but stint on the pleasant things. I'm not doing any singing, simply because I'm too tired to go out in the evening after work. Perhaps a foolish priority, but some things just have to be done. I start becoming more and more agitated about the behaviour of people around me. Ordinary, simple things though, things you only notice if you're sick.

For example, the bus driver who wants to leave two minutes early, sees me coming and pretends to drive off. Then he stops again, opens the door and says sarcastically: 'A brisk walk won't do any harm!' Uhh no, that's not going to work Mr bus driver. 'I have cancer and I'm exhausted!' Then I think, '#&\$#!', but I don't say it.

Or a supposedly good friend who cracks a really stupid joke, which really upsets my husband, who is also at his wit's end. My husband reacts angrily and tells him to keep his bad jokes to himself, because we are preoccupied with other things, like a wife with cancer. Later on, in the middle of the night we receive a text message back. 'Yes, and? I have just gone through a divorce, so I think I'm allowed to crack a joke.' Empathy is wasted on some people...

Well, it's just not worth it. Some cheat and 'choose' to leave their wife, with all the nasty associated consequences; others become ill, obviously something they did not choose. But everyone feels their own pain most intensely. Sometimes you cannot be there for each other.

I had counted on him, but this friend cannot separate things and is busy going through his divorce; that is his pain. In turn, he will feel that we abandoned him because we just don't have the energy to listen to the same story over and over. Be happy with what you do have! You have a new girlfriend! You can still go out! You can still pick a fight!

When you get sick, you have a completely different perspective of the things around you. I wish him well, and for the children's sake I really hope that the divorce is not too traumatic and is resolved quickly, but this friendship is over for me.

Does being sick make you selfish?

However you look at it, the fact that I am disappointed is based on expectations. And I must stop that. I look at myself and ask the same question again: 'Do I think about myself too much? Am I selfish? Does being sick make you become selfish?' But actually I know deep in my heart that I am not selfish and that I have every right to think about myself at this time.

But enough wallowing in self-pity. Back into the fray, with a few less friends. More will follow.

FINALLY A DATE, BUT FIRST A HOLIDAY!

Surgery date

The date of the surgery is set! 22nd August 2012 is the big day. At last. I'm just relieved! Also weird: How can you be happy about an operation where they are going to remove a complete organ? Well I can tell you: I'm happy! Not that I'm going to be missing an organ, because I don't have the foggiest idea what that means exactly, but I'm going to get rid of that cancer!

Turkey, twelve points!

I understand that it is better for my body if I delay the second operation and that I have enough time because of the nature of this type of cancer. So I'm first going to enjoy a holiday with my family. All four of us are ready for that.

My husband is so tired that we decide to fly this year. Instead of the twelve hour trip to Austria that we have been making for years, we're going to fly to Turkey with the children for the first time. To just relax; only the sun, sea and beach.

As if they know what we've been through in the past year they give us a penthouse instead of the rooms with an adjoining door that we booked. A complete upper floor at our disposal, with five rooms in a row. For ten days we live like God in France, only in Turkey. For the first time in a long time, cancer doesn't exist. Here in Turkey, I am anonymous, cancer free!

Preparations

Back home, preparations for surgery begin. The stream of cards, loving messages and flowers that I have received since the diagnosis, just goes on and on. But, unfortunately, a feeling of despair also returns with seeing the cards. I try to remain positive by filling my Facebook page with all sorts of uplifting quotations. So positive that

I even receive comments to the effect that I am too positive. Nothing is ever good enough.

Growing

However strange this time in my life has been, it has also brought a lot of good things. I have grown tremendously as a human being. Because of everything I am going through now and the way in which my husband and I are dealing with it, we are growing. It's strange that I haven't felt so strong for a long time.

Several years ago, I went through a reintegration project with a coach, a Buddhist. After knowing me for just five minutes, he said: 'Anke, you are a strong, exceptional woman and you possess more strength than you think possible.' I had to laugh, but now I see it myself!

These words are repeated to me from unexpected quarters. An old school friend who saw pictures of my family on my Facebook page says: 'I like looking at your photos so I can believe in love again, you are an exceptional person.' What a beautiful thing to hear. Or another acquaintance, whose partner is seriously ill, who tells me that she and her partner look at my positive quotes on Facebook to both gain strength. These things make me grow.

Dip

Despite the positivity I must admit that I've been sleeping poorly for a few days. I suppose that things which don't emerge during the day have to come out of my subconscious at night, one way or another. Well, naturally it has to be processed somewhere.

As quickly as I feel strong and full of fight, this feeling subsides again and I go through a major dip. I feel as fickle as the weather. I seem to get stuck, I feel all alone, sombre and searching for a silver lining. Maybe deep down inside I feel as if something is hanging over me, like the sword of Damocles.

BYE DEAR MUM

Telephone

All of a sudden, amidst the preparations for the surgery that will take place on 22 August, a massive blow comes out of nowhere. My mother passes away on 31 July. Just fifteen minutes before that, we were still speaking to each other over the telephone. She was going to call me back shortly, she said...

The week goes by in a blur – the arrangements, the cremation. I would have liked to have sung for my mother, but after the operation in April I still can't sing as I'd always done before. I sing 'The day your mother dies' by Karin Bloemen silently in my head. The words just won't come out. I can't grasp what has happened. It's happening so fast. There's too much going on in my head.

I'm not able to process the feelings that are flooding through me after the death of my mother. I suppress them completely. I cannot cope. I replay the last telephone conversation with my mother thousands of times in my head. The words of my father: 'Mum is dead' are still echoing. I don't understand.

I hadn't seen her again since my operation. I blamed her for that. I needed her so much and now she's dead. I feel terribly guilty, because I know there were good reasons for not coming. I feel like I'm being selfish. It's an irrational way of thinking.

In our last conversation we spoke about things openly, we were honest with each other, as we always could be. That is what counts. I need to stay strong for the operation, for the treatment that is going to come. I switch to auto-pilot. 22 August is fast approaching.

Heaven

A week later I'm sitting on the bus on my way home from work. My thoughts are with my mother, as they have been every second of the

day since 31st July. Dazed, I look up at the screen with travel information to see if I'm on the right bus and with a feeling approaching happiness I read: 'next stop: 'Hemeltje' ("Heaven")'.

Well, I'm rather glad that I can just get off at my local bus stop and not in heaven, but it almost seems as if my mother is announcing that she had arrived safely. We always did that, let each other know that we had arrived safely when we went on holiday.

The proverbial last straw

I think that now I am officially eligible for a nervous breakdown: I want to ask those who are experimenting with voodoo dolls to stop it IMMEDIATELY. My children have their birthday on 10 August, 15 years already; time is going by so quickly. The day starts well: breakfast, gifts and a trip to a massive indoor water park where the four of us will spend a pleasant day. On the way there, a warning light comes on: 'Replenish coolant'. Strange, because we had just done that.

On the way back we first topped up and then set off home. Ten kilometres further, the warning light came on again and at the same time a red light: Engine overheating. Luckily we stopped in time, because smoke started coming out of the bonnet. And there you are, somewhere in the middle of nowhere, miles away from home. Called the AA road service; they towed the car. We were taken to a salvage company, where our neighbour collects us. Hours later we arrive home. Of course, the birthday was a let-down and now we were without a car. I wonder when it's going to stop, all this misery at once. In order of importance with death and cancer, the car is somewhere at the bottom of the list, but it is just the proverbial last straw.

Nevertheless, we still celebrate the boys' birthday and that of my niece who has a birthday around the same time at my brother's house with my family. It was a mixed day. Good to be with everyone, especially for the dinner at the end. But also difficult because of the absence of their grandmother, the empty chair next to my father where our matriarch normally sat.

OPERATION THYROID CANCER, PART ONE

Sick – now what?

After the sudden death of my mother, I prepared for the surgery on autopilot. A week before the operation I paid an urgent visit to the medical centre. I felt very tired all day, could not focus and was icy cold.

I had called the GP earlier that day to ask him to prescribe something for sleep that I can collect that afternoon. I returned home from work a bit early, because I felt really awful. Picked up sleep medication and I went to bed. I fell into a wonderful sleep, but woke up with a temperature of 39.7°C. Actually, I had no other symptoms aside from a rather high fever and I never get fever. And I was short of breath, but that had been the case for weeks.

At my husband's insistence, who was worried, I called the medical centre. I had to come in case of another possible bout of pneumonia. Fortunately that doesn't seem to be the case. The sudden high fever is probably a reaction to exhaustion. That's not surprising after what I've been through recently. I'm told emphatically to take it easy and hope that the fever subsides, otherwise the operation won't proceed. Not really the sort of thing you should say if I am supposed to remain calm; of course, it stresses me out. But anyway, I stay calm, because the operation must go ahead.

Day of the operation

The fever is gone and on 22 August I leave for the hospital in the full expectation of reporting for the operation at 10.00 hrs. I am second on the list. Today, the cancer is finally going to be removed!

I am prepared and nebulised because I'm asthmatic and have been very short of breath in the past few weeks. After that I wait to be taken into surgery. But no-one arrives, until 15:30 hrs.

Enough!

From 24.00 hrs the previous night until 15:30 hrs the next afternoon I have not had anything to drink. Dehydrated and tired of everything over the past few months, I break down.

Not once has somebody bothered to come and tell me that the operation will be delayed or to see if I am alright. At 14:30 hrs PM I called to ask for something for my nerves, because I could no longer cope with the stress and the pain in my back. No medicine was forthcoming, but an hour later the resident physician arrived and told me that the operation won't proceed today and they had not yet arranged a new date. That's when I became really upset.

Everything I had resisted over the last few weeks, from the moment on 26 April that I heard that I had cancer to fighting to get surgery done, to the death of my mother on 31 July, to the day of the operation, today, 22 August....

I'm done with it, done with fighting!

Angry

I vent all my emotions there. From the time of diagnosis I have had to fight for recognition and to be taken seriously. At first, they just wanted to leave things as they were, despite finding three spots separate from each other. After weeks of going back and forth, they eventually decide to operate but now it won't be happening after all. I've just had it with being strong. The fighting, the death of my mother – it's enough already. I fully appreciate the fact that an operation might run late due to setbacks, but they already knew that by 12.00 hrs, didn't they? So sitting there for all that time with all the stress and without anything to drink until 15:30 hrs was completely unnecessary. It's just that I'm tired of the way that patients are handled.

As if it's no big thing: if you do have cancer, this type of cancer would be the preferable one. As if you are lucky! I don't understand why someone who is diagnosed with cancer would have to fight for recognition. It is only logical that you want to have the cancer remo-

ved from your body, but no. It's about thyroid cancer so: what's the big deal? It's a good type of cancer! Grows slowly, so it doesn't really matter. Enough of this!

Like a deflated balloon

It is a complete outburst, perhaps somewhat more intense than I normally would have made. I realize I have a lot of issues to work through. I always thought: everything will come right as soon as I have had surgery. Then I will have enough time to permit my feelings. But then the operation didn't go ahead – I deflated like a balloon with too much air.

I am going to use the days before the new operation date to settle myself and to rest. Because it is readily apparent that I am exhausted. My resistance is low, I have lost 6 kg in a week and a half. Normally I would have been very happy about it, but this is not healthy.

A new date

In the hospital too they were unhappy about the way things had gone. The surgeon contacts me personally, apologising for the lack of communication and apologising that the operation before mine ran late.

Things are quickly set in motion and I can go under the knife the week after, on Wednesday 29 August. I'm first on the list. I can report to the ward at 07.00 hrs in the morning and then hope that everything proceeds. I'll believe it once I wake up in the recovery room.

OPERATION THYROID CANCER, PART TWO

Attempt number two

After the failed first attempt we are underway with attempt number two. On 29th August at seven o'clock in the morning I report to the same nurse as the previous week, who greets me heartily with 'Hey hun, you're back again!' Things happen quickly.

The surgeon visits me briefly, I am nebulised and before I know it the ever-cheerful transport service arrives to fetch me. This time the ride to the operating theatre is very different from that of the first operation. I'm completely lucid and conscious. I've only had paracetamol and no dormicum.

I consciously climb onto the operating table, consciously let myself be tied down and am fully aware of the IV needle and heart monitor, blood pressure measurement, etc. I think I actually am more at ease because of this than the first time. I still have the vague idea that I'm in control. I am also able to answer questions myself and we laugh in the operating theatre until the last moment. I go under with dreams of Turkey in my head. The nurse who secures me is the hammam masseuse and the bright operating light suddenly looks like the Turkish summer sun.

Goodbye cancer

I wake up 100 times better than on the previous occasion. On the morphine I float gently back from Turkey to the reality of the recovery room. Like the first time, I am lovingly awakened by my choir mate, who specially swapped her shift to be with me. To wake up so wonderfully with a loved one next to you.

Once back in the ward I have a delicious gingerbread biscuit and in the evening a plate of spaghetti! It tastes better than expected.

What I can't eat, my hungry teenage sons do. With my family around me I consider myself fortunate. I am rid of it!

The pain stays away until around dinnertime. A shot of morphine, paracetamol and diclofenac do wonders again. Before going to sleep another heparin injection to counteract thrombosis and calcium as a precaution, because they are not yet certain whether the parathyroid glands have been retained. Reassured that my body is rid of the cancer, I drift off to sleep.

The day after

The night after the operation I slept well and woke up feeling quite fit the next morning. The doctor did his rounds early and explained everything to me. I can start T3 immediately. This is administered as an 'interim medicine' for two weeks, to suppress the major symptoms of losing a thyroid gland. Then I may not take anything for a few weeks prior to the radioactive iodine treatment. After the iodine treatment we will start the standard thyroid hormone levothyroxine T4. If my calcium levels are good I can go home. However, I should take into account the risk of pneumonia. I'm still having difficulty with mucus and that must be expelled.

They nebulised me three times in the hospital. Before and after the operation and once more on the morning after the operation. I really should not complain. The operation went well; according to the surgeon a large amount of tissue was removed and the parathyroid glands were spared. The calcium level is checked by drawing blood, because I did have severe tingling in my fingers and toes. As a precaution, I have been put on calcium tablets.

Of course, I will only know in a few weeks whether or not the vocal cord nerve has been damaged, but I suspect that it is intact. My intention is to start singing the following week. Joe Cocker is famous for his raw, husky voice; I can do that too...

Unsure and frustrated

Unfortunately, my first night at home didn't go that well. I nodded off on the couch and woke up later with a huge lump in my throat. I constantly have the feeling that there's something in there that I have to swallow. There is also a lot of mucus. Whether this lump is mucus or swelling is not clear. I am advised to get in touch if I have trouble breathing. Talking is very difficult because of the lump. If I talk for any length of time you can hear the wheezing of the mucus. The T3 makes me feel terribly agitated. I need to get used to all those medicines. What time may I eat and what time do I have to take which tablet? Half an hour before eating, two hours after eating. You'll probably get used to it.

The scheduling of all appointments with the endocrinologist, the nursing consultant, the surgeon and the drawing of blood is confusing me. I'm don't drive. Because I sustained whiplash when I was younger which caused me to suddenly lose consciousness a few times a day, I never obtained my driver's license. Now I don't dare attempt it. It remains a future goal, but of course I can't do anything about it right now.

Because of this I am dependent on my husband, but he has to work all the time. He spends his time criss-crossing half the country. I can see that the events of the last few months have worn him down and I am concerned. I want to protect him.

I am thinking of calling a taxi and going on my own when it suits me. Everyone says 'Take it easy girl', but so far I've only been home for half a day and I have way too much to do. In turn, my husband doesn't understand what I'm concerned about. He just wants to take care of me. Isn't it obvious?

But I'm not comfortable with everything. I just want life to return to normal. I don't want to be a burden to anyone. I just want to be a mother, a wife, an employee, and a soloist in the choir. I want to be able

to do everything again. Not to be dependent on anyone and certainly not be a patient!

I feel misunderstood, agitated and miserable. Are these the familiar post-surgery blues?

Calm

The nursing consultant calms me down. I have to get used to my new body, from which something is missing. Get used to the medication and to the hormonal issues. I am probably also reaching menopause at the same time, she tells me. The hospital is going to call me back to schedule the appointments, it will all be fine. My voice is not strong enough to arrange everything and I simply let go of it for now. Tomorrow is another day.

CANCER – BETWEEN YOUR HEART AND HEAD

I'm literally stuck between my heart and my head. More and more I realize that I am very sick and I also realize that my mother won't be coming back. My family will soon visit me. They all come – except my mother – and it's her shoulder that I need to cry on. That longing for her, how I have missed her, were the last words that I said to her on 31 July. It hurts so much.

How do we go on?

Today I got up with only one thought: 'How do I turn things around again?' How do I adopt a positive frame of mind again and how do I ensure that my hormones return to normal? I'm in a very negative spiral and I will and must snap out of it! I'm only descending deeper into the pit.

That also has a physical impact; I am terribly constipated. I dare not even go to the toilet because the pain makes me scream (figuratively, because I cannot actually scream). It's like passing stones.

My hormones rage; up and down, left and right. I know it's part of the deal; it is one of the symptoms of not having a thyroid gland. But I decide to resist it for all I'm worth, because it's not what I want. I want to be happy and positive! I want to be able to fight again and all I'm doing now is receiving blows. I don't know myself. The realisation that my life will never be the same again, is gradually taking shape. But that's not to say that I am clinging on to the past. A new life started when the cancer was cut out, perhaps with limitations, but no less beautiful.

Going for a walk is now like sport!

This morning, I was able to wash my hair. Even small things like that make you feel better again. Personal care is and remains an important ingredient of making you feel human again. Yes, this is going in the right direction.

Today, I went out for the first time, for a stroll to the GP. Wonderful, it makes me feel human again. It really is a workout though! But it went well and physically I actually feel pretty good.

The visit to the GP went well. Because I was having difficulty with one of the sutures, she cut off the ends and on the one side even removed a large section. The wound is closed nicely and is healing well.

I must honestly say that I don't have any issue with my scar. Nor did I after my first operation. It's part of me now and tells a story of victory. The GP is still hearing slight wheezing over the lungs, so there is still mucus. That remains a concern, but everything is okay if I don't develop fever.

ET with a sore throat

Meanwhile, a week and a half later, I can say that things are going in the right direction. I can't really complain except for the occasional hormonal dip. I enjoy the visits, messages, cards and bunches of flowers. Life is taking on a normal tone again. Hubby is enjoying work, the children are going to school and being their normal teenage selves. Yes, this is going in the right direction!

In a little while I'll be singing my heart out again, but I have to be patient about that because I sound like ET with a sore throat. I have every confidence that it will be fine, because I can hear that I can reach the right notes when humming. Meanwhile, I am having a really good laugh at a portrait that a choir friend made for me titled *The voice of ET*.

Next week, I will receive the pathology results for the thyroid gland. I'm not worried. I feel that everything is alright and most often my instincts are correct.

THE CANCER HAS BEEN REMOVED, SO ARE YOU BETTER?

I have good news! My instincts didn't let me down. There are no malignant cancer cells to be found in the other half of the thyroid! No metastases and the parathyroid glands have been spared. However, signs of inflammation were found indicating Hashimoto's disease (a chronic inflammation of the thyroid gland) that was probably already present. This explains all the symptoms that I had for years. It does not affect the way forward, the treatment simply goes on, but my prognosis is better. I'm stamped as 'low risk of recurrence'.

In addition, they took blood samples and we discussed the possibility of consulting a medical psychologist. At this stage, this doesn't appear to be beneficial to the endocrinologist, because my hormones are still raging and too many things are still up in the air. Too unsettled. A psychologist cannot remedy that at this stage. At a later stage, when the treatment with radioactive iodine is over and I'm receiving the correct dose of thyroid hormone, this can still be done.

The reasoning behind this explanation is clear and I put the idea on hold. I will first have to go through the hormonal imbalances. Next week I will hear more when I'm going to the nuclear medicine specialist.

Unfortunately, I develop a fever. If this persists, I will have to call the GP to discuss whether there is an infection and they will inspect the wound next week.

Dealing with good news

For one reason or another, I have difficulty with processing the good news. That sounds quite strange and maybe it is, but let me try to explain.

Everyone around me tells me how happy I should be. Some of them don't have an inkling of understanding and even say that I no lon-

ger have cancer; so let go. What are you complaining about? You are better now aren't you? Seemingly, this is a logical assumption for healthy people, because I hear it constantly.

Regrettably, things aren't that black and white. No additional cancer cells were found in the resected tissue, but they were present in the first part that was removed in April. What's the significance of this? It means that cancer cells were growing in my thyroid tissue, but you can never remove 100% of the thyroid tissue. So there could be microscopic particles in the remaining tissue, making additional treatment and a scan necessary. It works the same way as removing a sticker. Once you have pulled a sticker off, a very thin layer of glue remains behind. The same sort of thing happens with thyroid cancer. That they haven't found anything improves my prognosis. Naturally, I'm happy that this is the case, but strangely enough I have a lingering gut feeling which I don't want.

Surgery in vain?

Not only do I hear that you are healed when the cancer is removed. There are even people who claim that I underwent surgery for nothing, because nothing was found in the second half of the resected thyroid gland. The familiar 'You see, you should've listened to the surgeon; why do you think he didn't want to operate?' soon follows.

That's what you get for being too open, saying too much. People have too much information and sooner or later they will throw it back at you. Right now, that's difficult.

Let's see how people deal with it when they have been diagnosed with cancer. Then I'm interested to hear what choices they will be make. I don't for one moment regret the second operation, despite the consequences. I am more reassured now than I would be knowing that the cancer is still in my body. I am and remain of the opinion that the choice must lie with the patient personally.

ET passing stones with a throat infection

Today, for the umpteenth day in a row, I'm having terrible difficulty going to the toilet. Every day I try and every day I pass rock hard stones. It causes tremendous pain and bleeding. I suffer from IBS (irritable bowel syndrome) and have a lot of tearing because of the constipation. These wounds keep reopening. The hypothyroidism that I currently have makes my symptoms worse.

In addition, I am really tired, have difficulty swallowing and my voice does not want to cooperate. The endocrinologist has already mentioned a speech therapist. I'm a little scared of that; she assumes that it won't improve. Well, I actually do. I refuse to keep sounding like ET with a throat infection. I have started humming to exercise my voice and gradually noticed a steady increase in range. It's going to be just fine.

I am going to see the surgeon tomorrow and will address this. I'm hoping to hear when I will be admitted for treatment with radioactive iodine. Hopefully it will happen quickly, because I see the RAI treatment as phase two after the operation. That means a step closer to phase three: balancing the thyroid hormone, which will allow me to feel completely human again!

A ROLLERCOASTER RIDE

Long live the nursing consultant

I have just come home dead tired from a busy day at the hospital. First, blood tests for calcium, because I'm still having tingling sensations in my fingers and toes. After that, a very emotional discussion with the nursing consultant, who showed a lot of understanding and listened well. Filled in the 'Symptom meter' to monitor practical, psychological and physical problems. This visit is a valuable supplement to the doctor's medical care. There is plenty of time and attention to me as a human being!

Then to the surgeon. In principle, all is well. The fever is due to fluctuations in the thyroid hormone. Normally, the thyroid gland regulates your temperature, but my body is searching for a solution. The wound is healing well, but there is a lot of internal scar tissue pressing against my oesophagus and trachea, which makes me feel like someone is pressing a thumb on my throat. It will pass, but it will take some time and most likely even longer because of the RAI treatment.

If it still bothers me after that, I can consult a physiotherapist to massage the scar tissue. The surgeon is now scheduling an appointment with the nuclear medicine physician; then I will have a trial run after which I will go into the bunker for a few days. Because I don't know exactly what this entails, we decide to calmly wait until it happens.

Life is a roller coaster

My feelings are all over the place. I'm not doing so well. I'm still passing stones, have put on a few kilograms and my emotions are on a rollercoaster ride from happy to totally depressed to paranoid. My thoughts vary from 'no one likes me', 'no one wants to be my friend' and 'my employer no longer wants me' to 'intensely happy with people around me who unexpectedly show love and understanding'. I try to focus on the latter.

For example, what would I do without my dear neighbour? She is always there for me. These days, even making a cup of coffee for me is a lifesaver! As are many other things.

I've hardly been on the PC for a few days, not on Facebook, not on forums, just to check my mail and then turn the PC off again. Actually, it was great. Taking time out for myself and my three men at home.

I'm busy making plans to clear things up: to find an appropriate place for photos and things like that. Every day, I must set aside half an hour to exercise and accomplish other things. I must draw up a plan and have enough discipline to see it through. But it's difficult, because I can't remember things at the moment. I forget everything; 30 minutes later it's gone again. I assume that this will go away, as soon as the medication has been set properly.

Hormone bomb

Someone from the Nuclear Medicine Department has just called me: I must stop taking the T3 on 2 October. It turns out that on 16 October – our anniversary (married for 16 years) – I must go for trial treatment, a capsule or, if I have problems swallowing, an injection. Then, this must be left for a few days to take effect and I must return for a scan on 19 October, to measure how much radioactive iodine will be necessary for the treatment. After that, I will be told when I will be admitted for the RAI treatment. Probably around 23 October. On to step two.

Fortunately, I am given written instructions as well, because I will forget half of what I have to do. But I know that everything will turn out well, so on to 2 October.

What I do not look forward to is stopping the T3. I already feel really rather ill with the current low dose of T3. What is going to happen when I'm no longer allowed to take any thyroid hormone? I imagine that it will be a very miserable time. Actually, most of my sympathy is for my husband and children. They are the ones who are going to suffer most from this hormone bomb.

The Living Dead

Physically, things are getting worse. That's what I'm fed up with. After the first operation I recovered well after the first few weeks, but now I'm really regressing. It's a logical consequence because my body has to compensate for a missing organ. I walk around like a zombie from the movie *The Living Dead*. My husband says I am so white and lifeless that all he has to do is shroud me in a coffin. And that's how it feels. Very slowly I feel myself deteriorating. Just hang in there!

My feelings are still all over the place. I'm not doing so well. Neither physically nor mentally. The after-effects of a pleasant day are burdensome.

I feel terribly alone, often misunderstood. I often respond to things too drastically. This is also something that others can't understand. I am sorely in need of rest, together with my beloved husband. But if I say that, I exclude my children. That is not the intention, but sometimes I just want to spend quality time together as husband and wife and not always the four of us.

The children's attitude is sometimes not conducive to enjoying quality time. The constant bickering of my two teenagers throughout the day wears me down. I don't have the patience for it at the moment. I even think that the temporary isolation in the bunker might be a good thing. More and more I am thinking about really isolating myself for a period of time, even without a laptop or telephone. I am so tired. Like a broken butterfly.

HAPPY SAPPHIRE ANNIVERSARY

Before I have the trial treatment on 16 October, we are going to celebrate our Sapphire anniversary (16 years) in a wonderful wellness suite near Utrecht. This suite really has everything needed to make me feel human again: a Jacuzzi, steam shower and a sauna-for-two in the en-suite. What more could one want? Well, okay ... aside from being healthy?

The trial treatment

Meanwhile, I've had the trial treatment: a capsule with a low dose of radioactive iodine-131. In this way, a scan is used to determine how much radioactive iodine-131 will be necessary to banish the residual thyroid tissue from my body.

After the capsule, the level of radioactivity is measured in the neck. This is done externally, by keeping your neck motionless in front of a meter. The thyroid tissue then needs another few days to absorb the radioactive iodine. With a repeat measurement, a blood sample and a scan they subsequently determine how much thyroid tissue is still present in your body and whether the radioactivity has been absorbed.

I'm allowed to have the scan and the measurements a day earlier than scheduled, and I will also be informed of the admission date. Soon after taking the radioactive iodine capsule I suddenly feel sick. We go home and watch a comedy.

Now I feel really sick. Nauseous, dizzy, ... I have to run.

Scan and measurement

Fortunately, the day of the scan comes quickly and I report to the waiting room at the Nuclear Medicine department. I don't like this waiting room; I feel uneasy every time I go there. Not a place where you like to spend time. A couple with a small baby emerge from a hallway

with large yellow stickers on the doors and I consider myself lucky. I know that I will get better. A little later I get to go through the same iron door myself.

Good news

Today, the scan shows that there is very little thyroid tissue left in my body. The surgeon has done extremely good work! The result is that on 23rd October I am admitted for the RAI, but with a third of the usual Megabecquerel (MBq – is a measurement unit for radioactivity). The usual quantities of MBq used to destroy thyroid tissue, are between 1850 and 3700 MBq. With me, they want to start with a quantity of 1100-1400 MBq. This is so low that the admission duration will probably be Monday to Wednesday, perhaps even only until Tuesday afternoon. This depends on how rapidly the radioactivity breaks down.

With a radiation level below 20 you can return home, subject to a strict regimen. For me, the regimen is: no physical contact with my two teenagers for a week, no physical contact with my husband for two to three days and keeping a minimum distance of one meter from pregnant women and small children for two weeks. But by the time that I am allowed to return home they will reiterate this in detail in the hospital.

I am then given a tour of the so-called bunker in the ward, where I will have to spend these few days. I can't reconcile the expression 'going into the bunker' with the room shown to me by the nurse. It is a beautiful room. I should be able to hold out for at least a few days here. I return home in a good mood. I must report at eight o'clock on Monday morning.

I'm going on a trip and I am bringing...

Monday is fast approaching. Until now my nerves have been better than expected. I calmly go about making preparations. What should I take with me? What won't I have to bring back?

I don't pack my best clothes, because it is possible that these will be contaminated by radiation. I understand that all the things I take with me – just like me – will be measured when I go home. If the measurement is too high, they will have to stay behind or be destroyed. For my toiletries I pack disposable items. Travel size packaging of shampoo, toothpaste and shower gel. Magazines that will be discarded once read. My brother gives me a number of gifts to take with me. A gift for each day. The first gifts are a card to wish me luck, a pen and a green notepad to record all my experiences. I will certainly use these.

Tomorrow, I'm going to install Skype on my laptop, which I can take with me if I wrap it in foil. I hope that the side effects will be limited, so I don't have to race to the toilet as I did after the trial treatment, but I decide not to concern myself about that, because I have no control over it.

I spend Sunday relaxing at home. A day filled with cuddling, because from Monday I won't be able to do that for a week – something I'm really dreading.

GLOW IN THE DARK ANKE

At 08.00 hrs on Monday morning my husband and I arrive at the desk of the 'bunker' section at the department of Oncology. We are soon taken to my room. The lead doors have the familiar yellow sign: 'Note: Administration of radioactive substances!'

The room is very spacious with a breath-taking view! I have a television at my disposal, free Internet, an exercise bike, a pile of magazines and a bowl filled with sour balls. After ten minutes, my husband and I have to say goodbye. I already said goodbye to the children at home. They may not come into this section, because they are under the age of 18.

Sour balls and lemonade

Meanwhile, I've been installed and I've been given the pill. What a palaver about such a small tablet. A Nuclear Medicine staff member in protective clothing arrives with a trolley. On it, a secure container with the goods. He uses pliers to remove the capsule from the packaging, and then drops it into a type of pipette tube. Then I must throw it into the back of my throat as you do when gulping something. After that, the staff members immediately move back a meter and use a stick to check whether the radioactive iodine has been properly ingested. Then the initial value is measured; something they will repeat a number of times until you have reached a certain level below a norm stipulated by the authorities, after which, in principle, you are allowed to return home subject to a strict regimen.

The sour balls, which look very good to me, are there for one purpose. They ensure that you have less tingling on your tongue or in your throat and that there is less chance of a loss of taste. I was told to drink a lot, because iodine that is not absorbed by the thyroid gland, is excreted from your body in the urine. This occurs mainly within 24 to 48 hours. That's nice, because the lemonade in this hospital is the

best I have ever tasted. That's really no punishment. The radioactive iodine that is absorbed by the thyroid leaves the body at a much slower rate and therefore you are measured again before you can return home.

In 'solitary' confinement

So far I feel okay, but the expectation is that I will become nauseous. With the trial treatment on Tuesday I became very nauseous and even had to throw up. This quantity of radioactive iodine is much higher. We'll see. I've been given something for this.

I keep myself busy browsing the Internet, writing and reading and I'm actually relaxing. It doesn't feel like the complete isolation I read so much about. I do understand that this differs greatly from hospital to hospital. The catering staff don't seem bothered and come in with food and drinks. Although they put it down very quickly, they don't place it outside the door or pass it through a hatch. The nursing consultant also makes her rounds. She only stays for precisely 2 minutes and keeps a 2.5 meter distance, but she does come by. I really appreciate that. I realise that I've been very lucky. So much tissue was removed during the surgery that this will probably be over relatively quickly.

Until now, the overwhelming symptoms during the period without medication have been the worst, but I hope that these will disappear rapidly now. Three days after arriving home, they want to put me on a cocktail of Levothyroxine T4 in combination with T3. I'm curious.

Then, the following Monday, another scan and if everything is okay, back to the endocrinologist. It's a good thing that I was able to bring my laptop with me. In the evenings, I Skype my three men and then go to sleep early. Before I know it, it's morning and maybe I can go home today.

Glow in the dark

As always, I have to go to the toilet in the middle of the night. I'm not able to locate the light switch. So I leave it off. But I can see a faint light.

I look down: it's me giving off the light! A luminous stream lands under me in the toilet bowl. I had a good laugh about that. What a funny look: Glow in the dark Anke!! In the semi-darkness I still have to observe the rules of the toilet: sanitary towel in your underwear changed with every toilet visit, clean the toilet seat and of course, wash your hands.

Going home

This morning I got up with the feeling as if I had been on a tremendous binge the previous day. If only it were true, I would have enjoyed that. I'm not really having difficulty with anything else.

Fortunately, the nausea never struck. I was even visited by a work colleague and a fellow choir member. They were given permission to visit me, at a distance of one meter. After breakfast the doctor comes to take measurements. My radiation level is 9, so I can certainly go home today. My husband can come and fetch me after lunch. They go over the regimen again: not within a meter of my husband and children or other visitors, do not eat at the same table, do not sleep in the same bed as my husband and preferably use a separate toilet. Fortunately we have another toilet upstairs, so that's not a problem. As a joke, my children have stuck a 'radioactive zone' sticker on the bathroom door. In addition, I'm given a stock of sour sweets for the saliva glands. Not an issue, Napoleon balls, no problem at all. In about three days I can take T4 thyroid hormone together with T3. After a few weeks I will switch to T4 levothyroxine thyroid hormone. Another scan will follow on the 29th and if that is okay, which we have every reason to expect, I will go back to the endocrinologist who will make further adjustments to the thyroid hormone. Things can only get better after that.

When arriving home there is a small, but very great surprise: Gerritje, a parakeet, a present from my beloved husband. For 10 years I've been nagging for a bird and suddenly it's there. I am thrilled with my new family member. This bird is a gift of pure love and represents a new beginning!

LIKE A PARIAH

The regimen I must follow is burdensome. I am given the best present that I could wish for and I can't even really thank my husband with kisses or a big hug. It's terrible. To me, cuddling is a sign of warmth. I find that the finest moment of the day is when we lie close to each other in our 140 cm bed and fall asleep. Now we can't do that. My husband sits in one corner of the couch and I in the other. Teenagers are usually not that cuddly, but even to them it's strange. It won't be long and it's for a good cause, but it feels far from pleasant. The only one I can touch is my new friend, Gerritje the parakeet. There is no danger to animals because the effects only appear after 20 years and parakeets don't usually live that long.

Visitors

Although I can be in the vicinity of people outside a radius of one meter, I notice that people find it scary. Unlike after my operations, no one comes around. It's also as if I'm contagious over the phone. I attribute it to the unknown. I feel like a type of pariah, an outcast and I hope this passes soon. I sent my husband to work because we gain nothing by him being at home. Just when I'm feeling terribly lonely and sorry for myself, the telephone rings. A friend would like to come around for coffee. The objections I raise to put her off, she simply rejects. 'I wasn't born that scared', she says 'and if I know anything about you you're feeling rotten right now.' I emphasise that she can only come if she stays a meter away from me. When I hang up the tears are rolling down my cheeks. How well she read the situation.

This coffee visit transformed my week from one of being a pariah to a chance to enjoy a pleasant moment.

A white rose

The week goes by very slowly. Fortunately, my level of radiation drops to a level where my husband and I can sleep in the same bed after a few days and fall asleep next to each other. After a few days we can also eat at the same table, but not for longer than half an hour. I still keep a safe distance from the children. I hardly go outdoors. I don't want to run the risk of running into pregnant women. I do have plans to accompany a friend, who also lost her mother this year on 1 November, to the All Souls' Day mass in the town where my choir will be singing. In recent years I always sang at this mass, but this year I won't be doing that. That's not because I'm unable to sing, although I still don't have the power to sing as a soprano, but rather because I am too emotional to take part. This year, I will see it from the other side, as a survivor. As expected, the All Souls' Day mass releases many emotions in me and *The Rose*, which is an emotionally charged song for me because I sang it at my niece's funeral, cuts deep into my soul. Just like the white rose that I am given at the end by my fellow choir members as a symbol for the loss of my mother.

LITTLE PINK, WHITE AND BLUE ANISEED SWEETS

Triplets

Today, three days after the treatment with iodine, I start taking a cocktail of thyroid hormones (T4 and T3). The nuclear medicine physician has prescribed this to bridge the period until the T4 Levothyroxine takes effect. This combination of T4 and T3 is not always necessary, but because I have not been receiving any thyroid hormone for some time this is an attempt to help me get over the hypothyroidism symptoms as quickly as possible.

They are pretty pink, white and blue tablets. They do look like aniseed sweets, and from the colours we're having triplets! The joy of swallowing soon subsides because on the first day I suddenly start suffering from a carousel effect.

Things keep turning and turning. It makes me nauseous. I have to really concentrate on the letters on the keyboard because they float around a bit. I guess this is normal. Your body will have to get used to it. We are simply going to see what it will do, day by day. It won't make me hyperventilate, right?

Other than that, I feel a little off-colour. My throat remains swollen, the scar is stinging, I have terrible constipation and now it seems that I have also caught a heavy cold. Obviously suffering from low resistance. But I do not complain because the fact that I am on medication again means that I am a step closer towards healing.

Volcanic eruptions

Delicious those aniseed sweets. Not. Last night I had severe palpitations. They were as severe as a hardcore dance party on a Saturday night. It made me afraid and uneasy. The sweat was pouring off me. Chest pain, cramp in my arm. I have kept quiet about it because I don't want to alarm anyone. But the next morning my husband said that he had heard the thumping next to him. If only I had said how bad it was.

My hormones are all over the place. One day I am completely happy and the next day I erupt suddenly like a volcano.

This makes things difficult for my family. And for me too, because I regret it immediately, but then it's already too late. My husband is angry and sad because he doesn't deserve this! I have also caused the children pain, just when one of them was about to go to a fun school party. Fortunately, the text message with 'sorry, enjoy yourself' was well-received.

Repelling magnets

I notice that I have shut myself off completely regarding my feelings. Especially after such a volcanic eruption. I am simply not able to crawl back to my husband, who I love so much. I find that most difficult. As if we are two repelling magnets that want to come together, but cannot. I am totally at odds with myself. I feel terribly ungrateful, alone and monstrous.

I sit and cry about nothing and he may and cannot console me. That part is the most difficult for both of us. Why do I freeze up about it? Will it pass? Deep in my heart I know that everything will be fine. We have already been through so much together. We will emerge stronger!

Full steam ahead!

After a week of pink, white and blue aniseed sweets I have the scan. Exciting! We are hoping for a good result. The scan shows that I have good prospects for now, but regrettably I cannot yet say that I am free of thyroid gland tissue. The letter with the cancer-free stamp must wait a little longer. I'm a little bit disappointed though. I anticipated a result and I misjudged it. There are still small remnants of thyroid tissue to be seen in the intestines, lungs and in the lymph nodes in the neck. Apparently this is normal because the RAI continues working on those places where it accumulates the most and those are the intestines, lungs and lymph nodes in the neck. It will only be apparent whether I am clear in six months, after a second scan.

I am going to stop taking the boost of T4 and T3. The T3 must go, because I'm having a lot of palpitations and I'm not happy with the way in which I am reacting towards my family. Finding the ideal balance will take some time. According to the doctor it will take about six weeks before I will really start feeling better. Anyway, from now on I'm moving forward.

WHY?

Checking

My mobile phone rings at nine o'clock in the morning.

'This is the Social Security department. How are you Madam...? We arranged for me to call you today.'

'Oh yes, that's true... Totally forgot ... Glad I'm awake already and coincidentally just turned on my mobile. Well, things are so-so. I've just started taking thyroid hormone.'

'Oh, is that for your thyroid?'

'Uh, well yes, that is the hormone that will have to replace the thyroid gland.'

'Oh yes' – clearly not familiar with this – 'and how is that going Madam?'

'Well, it varies. Always one step forward, then one back, then two forward, then back again, something like that. It is just "Good times, Bad times".'

'Oh okay.'

'The endocrinologist says that it takes six weeks to start taking effect.'

'Ok, anything else, Madam? Have you had any contact with the health and safety service or a company doctor?'

'No, my employer doesn't want to place me under pressure and even comes to visit me regularly.'

'Well, Madam, that is admirable, something we regrettably seldom hear.' – I am happy to agree with him. –

'I realise that I can't complain. I regularly receive flowers, a card or a visit.'

'Madam, I'm going to call you back in a month or two to see how it's going. We expect that you won't be back at work for quite a few months.'

'Okay, thank you, Sir. Have a great day. Bye!'

Pressure is on

That was the Social Security department. 'Checking' they call it, an almost indifferent telephone call of about 3 minutes. Pretty strange actually. I expected a lot of pressure but that hasn't happened. I must say that I've always kept the lines of communication open with both my employer and the Social Security department – perhaps that's having some effect. Nevertheless, it's a weird feeling. My employer is not pressurising me, nor is the Employee Insurance Agency, so why am I placing myself under so much pressure? I'm extremely restless, I want to get back to work, go further, forward, forget and continue. The thought of sitting at home for another few months is already driving me crazy.

On the other hand, I'm hardly getting out of the house. I just stay inside. Occasionally, I have a cup of coffee with someone who comes to visit. Sometimes I even go for a walk outside with a friend. I really enjoy that. Now why don't I have the energy and perseverance to simply do that every day? The silly thing is that mentally I know exactly what is and is not good for me, but I don't do it! I decide that it must stop here and now. I'm going to start singing again! I must relieve the pressure that I am placing on myself.

After rain comes...

Meanwhile, it's not just doom and gloom. One of our children has been on exchange in Poland and we have to pick him up at school. The distance has done him a lot of good.

He had a great time and is full of stories. A little later we are sitting at home eating cake. He bought me a beautiful pair of earrings. How nice. Yes, he asked the girls for advice. 'What type of earrings should I buy for a hip mother?' So sweet! That evening we had raclette for dinner to celebrate him coming home. Now we are looking forward to the next step in the exchange, the Polish students coming to us.

Gerritje also brings me a lot of pleasure. He chatters to himself a lot. He clearly responds to me and to certain sounds that I make.

With me being at home for so long, it is the perfect time to tame a bird. He is getting better at sitting on my hand. I can cuddle his neck too. I can't really pick him up yet, so I don't dare let him out. But that won't be long now. He makes an awful mess and 'Good times, Bad times' drives him completely crazy. He screams loudly all the time as if he wants to say 'what a racket!'

LEARN TO SURF

What am I complaining about?

Longing for my mother sometimes overwhelms me. It's a grim reality which I have to face daily. Just being able to call her is something I miss terribly. About the stupidest things, such as 'what are you having for dinner tonight?' I notice that I cannot help my father with his grief, when I call him, and I find that awful. On the other hand, however confrontational, I try to see it as something good. The fact that I'm now at home gives me the time and space to grieve and put her death in perspective. I have to. Despite my nature, I cannot throw myself into my work to forget because I'm not physically capable of doing so. That's what I did when my brother's daughter suddenly passed away at the age of 22 years, far too early. Because I buried my head in the sand back then, her death has also re-emerged in my consciousness. If I look at it positively, I am using this time at home optimally. I have two deaths to grieve for and process. I am healing, recovering, resting, and even taming a bird: what do I have to complain about?

Stuck in a maze

That feeling of 'what am I complaining about' doesn't go away. But when I try to discuss it the response from my family and friends is 'girl it's not a minor thing. You do have to feel something! You can't just go on and on! You have to process things, ponder them and talk about them.' No, it is nothing minor. They are quite right about that, but nevertheless I have the feeling that I must comply with what is expected from others who are not as close to me. From them I hear exactly the opposite. You're taking the medication so you must gradually begin to start feeling better. Look ahead, push on and don't think about your illness too much. These are two totally contrary pieces of advice and I feel as if I am stuck in a maze. Where am I? Which direction should I go?

From wave to wave

Quite often I think tomorrow I will go to work again and we will act as if there's nothing wrong and then it will go away. I'm going crazy from sitting around, not being able to get out of bed, the muscle aches, the nausea, the fatigue and the tablets that I have to set the alarm clock for. And a day later I think 'what are you complaining about'. I can at least resolve it with a tablet. I can at least go on living. Just with a few adjustments I can continue with the people I love. Half a day later I'm stressed and I feel sick, while the hormones rage through my body. A day later I wake up and I look like I'm pregnant. For days I've been suffering from morning sickness. And then, after another day, I wake up and can't move my arms. My fingers are not nimble enough to pick up the little pills. A few minutes later I suddenly feel something and I suddenly realise that I have gotten my period too early. This is how it goes from day to day. From wave to wave. It's like learning to surf; I glide over the waves and every now and then I fall off the board, only to climb up again and continue surfing.

Who am I?

In between, I just get on with daily life. Cleaning, cooking meals, shopping. I also make enough time for pleasant things. I started singing again. I go out for the evening with work colleagues. But I don't enjoy these fun things. Why don't I enjoy it? Why can't I just think what I want to think? What other people say to me I would like to be able to say to myself. 'Girl, how lucky you have been!' On the other hand, these words make me angry, rebellious and sad. I don't want to whine and being negative is actually not in my vocabulary! I feel as if I'm in a game of 'Guess who?' They must have held up a very strange board when I pressed the button, because I don't recognise myself. Where has the ordinary, positive, cheerful Anke gone?

MIRROR, MIRROR ON THE WALL

After another tough night I wake up exhausted. Actually, I'm getting used to it. Although I would like to see it differently, the reality is that I'm exhausted throughout the day and for some reason or another I can't rest at night. You would think that I would sleep like a log, but on the contrary I toss and turn, I perspire, my tongue is as dry as sandpaper and so thick, that I am afraid I am going to swallow it. Halfway through the night my fingers take on a life of their own. They tingle furiously, are painful and it's difficult to get them moving. This is particularly annoying when I have to take my thyroid hormone tablet in the morning. I can't get the lid off the medicine jar and I drop half the contents on the floor. It's as if a train has run me over. Right now I'm so sick and tired of being ill.

But you don't look ill at all?

The previous weekend I went 'out' for the first time. A cosy reception for a colleague who has been promoted.

It was wonderful to get out again. Great to be with my colleagues who I had missed terribly over the recent period. An escape from being sick. Of course, I got all dressed up. I received a great welcome from many people who were quite surprised when I suddenly arrived. Clearly, I wasn't expected. 'Gosh, it's great to see you here.' 'You are looking good, you don't look sick at all.' Did they expect me to? That's the crazy thing about this disease. It's an invisible illness.

You feel wrung out, but you look pretty good, at least after a lick of make-up. If you respond to the question 'How are you?' by telling them how things really are, everyone is surprised. You don't see it.

Camera, lights, action

Actually, everyone says it. Girl, you are looking good! Previously, I would have been happy with the compliment, but now I would like to hit people.

On the other hand: appearances also count. In any event, I don't have to explain to anyone why I don't look good. Being a patient is not for me. I'd rather walk away from it.

Actually, it's come down to acting recently. Since I've been sick, I've clearly developed new talents. I should really play a role in a good soap opera. How are you doing? Well. Smile. I have missed my calling. Maybe I should go to an audition.

From 'The Grudge' to Vamp

Despite the fact that I got up feeling lousy this morning, I've done an awful lot. After the difficult start, someone came round for coffee. We have also arranged to go into town. I also had to go to the pharmacy, because the first jar of thyroid hormone was nearly finished. Eventually, I spent quite a long time in town. After that, I cleaned the bathroom in good spirits, did the washing and had a snooze on the couch to recharge. All in all the difficult day turned into a fruitful day. The only negative thing was my friend seeing me fresh out of bed in my robe without make-up and later on all dressed up with make-up. From Grudge to Vamp... can he get over that?

FROM QUICKSAND TO RESISTANCE

Despite feeling somewhat livelier, particularly in the afternoon and evening, than a few weeks ago, I still have many prominent symptoms. There have been moments when I'm thoroughly depressed. I resist those vigorously, because I don't want to feel like that. I find myself with tears running down my cheeks during a Disney movie. And feel like an emotional idiot. Physical discomforts like constipation, temperature fluctuations and dry skin are becoming worse rather than better. I have a lot of itching, pimples on my hairline and my scalp is so dry that there are flakes in my hair.

My hands and fingers tingle and sometimes my fingers just won't coordinate. Sometimes, my eyes don't function properly, my vision becomes blurred and my eyelids have a tic. I have the idea that my hearing is deteriorating. The fatigue and my concentration are a hindrance when going about my day. All in all, I basically just don't feel good.

I have written down a litany of complaints for the endocrinologist and want to discuss them the next time I have to go for a blood sample. I have the feeling that I'm not receiving enough thyroid hormone and have become uncertain about not knowing what is and isn't associated with it.

Quicksand

If you ask me how it's really going, this is my answer: 'I'm becoming a little dejected.' I find myself in a type of resignation, devoid of the will or spirit to fight. This is not a good sign and although I understand intellectually that I must break through this, I can't seem to pull myself together and do it. I make all kinds of plans in my head.

Plans about work, about sports, about getting out, about writing a book about the last six months –nothing comes of it. I think I'm going to schedule an appointment with the GP. Things are not going well this way. I feel like I'm stuck in quicksand.

I wrote this just after the thyroid cancer diagnosis in response to something that I read on the thyroid forum.

Sometimes I have the feeling that it's not about me, but that I'm an observer. I don't see this as a burden. I see what is happening and I deal with it. I'm going through this, because it is what it is. No stress!

This is how I saw it, but regrettably I have to concede that this feeling left when I faced the facts. This is the point I have reached now.

Resistance

No, I am not at this point! I refuse to submit to it. I will not go along with the depressive, downward spiral. It's the hormones talking, not me! I'm a positive, happy girl. I'm going to go back to work. I'm going to show the door to the negative people around me and make choices that are good for me and my family! I'm going to commit myself to thyroid cancer patients who, just like me, have lost the thread, who are overwhelmed by the feeling of being misunderstood. I'm going to show that despite the symptoms that come with this, there is still hope. Because there is hope!

After taking T4 thyroid hormone for three or four weeks I slowly begin to feel small changes. It does seem to be a matter of dosage. Spending an hour shopping or cleaning on the first day means that I have to pay for it the next. Because I'm an active person who can't get through things fast enough, this is occasionally a problem. But still, I have absolutely no regrets if I've had a great day and have to pay the toll for it the next day. On a good day I go for a morning walk. I've already covered five kilometres and I feel very satisfied and proud. The first steps on the way back to being myself have begun. It's going to be a bumpy ride, but I'll get there.

LIFE IS BEAUTIFUL

I go Christmas shopping with mixed emotions. The end of the year invokes feelings of warmth and happiness in most people, but I am angry and feeling rebellious. I am now really tired of being sick and want my life back. The attention given to 'Stand up against cancer' makes me even more rebellious. Filthy cancer!! A disease silently picking off people at random like a sniper. You don't see or hear anything about thyroid cancer. That touches me and makes me rebellious. It feels as if this disease does not matter. A confirmation of what I face in my daily life. And I'm not alone. I often hear this echoed by fellow thyroid cancer patients. This has to change!

If it takes too long, the understanding is often hard to find. People ask me questions like: 'Why don't you go out with us anymore, it has been a long time ago?' 'You've had surgery, so the cancer is gone now? So you should start feeling better.' 'Your chances of survival with this form of thyroid cancer are around 90%. So what? Isn't that what everyone has?'

Yes, that's right, but the fear you have and maybe keep having, the medicines you have to take for the rest of your life, the physical symptoms that you're left with? The impact it has on your family, your sexuality, your identity? The people who don't know what to say so you simply never hear from them again. But you should not complain, because at least you are surviving.

And that might be true. Surviving brings great happiness, so seize the day! Focus on what you still can do: breathing, feeling love, seeing your children, enjoying nature, music. And I plan to do that every day. I just want to focus on all the beautiful things out there!

The sun is going to shine

Yes, the sun is going to shine again. I'm on the way back. This week a friend took me to the forest to walk her dog. I was happy as a child!

Glorious freedom and the realisation that somebody had intentionally taken me with her to break my isolation – that makes me intensely happy! Gerritje who is becoming tame and chatting away to his new toys, going singing again in the choir and actually reaching the high notes, my children who let us put our Christmas stocking up. If my mind keeps doing its best like this and my body starts to cooperate, I'm going to totally own 2013.

Mind reading

As if my GP can read my thoughts, when I visited her this morning she said '2013 will be your year!' That must be a sign – I really believe it and I'm going to go for it. I poured out my heart to my GP. She supports my idea that it could be too little thyroid hormone, but whether this is actually the case is something I will hear on Tuesday, providing everything goes well at the endocrinologist. We are also going to monitor whether I'm not suffering or beginning to suffer from depression. According to the GP I am entitled to feel that way after this year, as if that's what you want. Well, not me.

Actually, my reason for going to the GP was something else – a week or two ago I suddenly developed quite a large bruise on my chest. It's starting to fade now, but since then I can feel a small marble underneath the bruise. The GP could also feel it clearly. Nevertheless, we are going to wait until the bruise clears up entirely, because it could also be a result of the contusion. I must come back before Christmas. The GP doesn't expect it to be anything serious. But I must honestly admit that I'm slightly panicky when it comes to lumps.

On the move

Because I told the GP that I hardly ever leave the house anymore, on my return journey I decided to visit a friend instead of going home. That was very pleasant and I intend to do this more often. Just to take the bike or walk. Get out there every day. I just have to do it, because

I do not want to suffer from a depression or those types of issues. I'm going to pick up the threads of my life again. I admonish myself about this and make arrangements to go to my workplace for coffee. Setting up the Christmas trees at work becomes my return project. Anke has to get out! 2013 is around the corner.

THE BEST MEDICINE IS WALKING

Although I lost a lot of friends this year, a few new ones have taken their place. And a very old friendship has undergone a rebirth. Out of nowhere we found each other again. It turns out that we have a lot in common. She has two beautiful dogs that need exercise and I can also use a bit of exercise, so we quickly arranged to regularly go walking in the forest. We drive to a forest with the dogs in the back where they can run around and we get to talk and enjoy ourselves. And it is certainly enjoyable! We have years to catch up on, so there isn't a lack of things to discuss. After letting off some steam we return home tired but satisfied and after another enjoyable cup of coffee there is a nice hug with the two beautiful dogs. Animals give so much love. Occasionally, you feel a warm tongue on your hand, as if saying 'I really like you!' It's as if they feel what you have been through and what you are feeling.

Also, the walks with my neighbour are becoming a weekly affair. The path across the dike is a familiar route. Even though I walk the same route every week, there is always something new to see. I will never forget the deer which came running out of the woods, right next to us. I truly enjoy it. Nature, the wind, being outdoors.

These walks have become very valuable to me. Of course the exercise in itself is therapeutic, but the discussions I have with these two friends are vital. They are my outlet. Literally. It has rescued me from isolation. It got me talking again. Where I used to keep how I actually felt to myself, now I talk about how it affects me. Slowly but surely I'm becoming human again.

Communication is a must

Unfortunately, my visit to the endocrinologist is a little frustrating. Actually, I still know nothing at all. I completely forgot about the list of questions I wanted to discuss. The consultation went by so rapidly.

I should really prepare myself better the next time. Communication is so important. A blood sample is taken, and I will get the results in due course. The endocrinologist indicated that the six weeks treatment with thyroid hormone is still too short to say that things are going better. That will take at least around three months. The blood test results will be used to determine whether the dose of thyroid hormone should be adjusted. An ultrasound has been scheduled in three months' time and another scan in five months' time, should this be necessary. I will receive a brochure at home about a drop-in centre for people who have or have had cancer who meet there to exercise or talk. I will wait for the brochure to arrive, as half of it goes over my head. Actually, I really don't know whether that is something for me. I simply want to pick up the threads of my life again. And since the walks, things are clearly going in the right direction. In January, two and a half months after the RAI, four months after my second operation, I want to consult the company doctor about returning to work. But first I am going to decorate the Christmas trees at work. The one at our home is already set up. I thoroughly enjoy it. The doctor's advice is: if I feel frustrated, go out for a walk.

So I take the advice and go walking in the snow on the dike! It's beautiful there, the frustrations fade away while simply enjoying the fresh air and natural beauty.

THE BREAST CANCER CLINIC

The telephone consultation with the endocrinologist about the blood results went more or less as I had expected. Provisionally, I may not increase the thyroid hormone, because it might go too quickly and I run the risk of becoming hyperthyroid: an excess of thyroid hormones that simulate a thyroid that is working too fast. I'm slightly unhappy about that, because I still don't feel well, but I must have more patience and that is usually my weak point. I want to do too much, too quickly. I still have to reconcile myself with the residual symptoms.

Do not think twice

Meanwhile, there are other matters that require attention. The GP has referred me for a mammogram. An X-ray of the breasts. For a while I've had a lump in my breast and it is better to be safe than sorry. Actually, I have hesitated for some time about notifying the GP about this, because I don't want to feel that I'm overreacting. That you suddenly become uncertain because you feel something again. The GP rid me of that feeling rather quickly. Do not think twice about things like that!

Fortunately, I don't have to wait long to go to the breast clinic. The breast clinic uses a rapid diagnosis method. Meaning going to the outpatient's clinic in the morning for an intake with the breast consultant and have a breast examination. Followed by a visit to the radiology department where a mammogram and ultrasound are made. If necessary, the radiologist will do an immediate biopsy. You receive the results the same afternoon.

Nerves

On the first anniversary of my mother's death we are on the way to the hospital. It has become a familiar road. The examinations go very well. Of course, it's not great to have your breast flattened by a press, but it is for a good cause. Waiting for the ultrasound takes forever. We make

the best of it in the hallway. Here we are again. Waiting, uncertainty. We haven't told the children where we are going and why, because we don't want them to worry.

In all honesty, I must admit that I am pretty nervous. I have become mistrustful about lumps and things that do not belong in your body. In that regard, I have become a bit of a stranger in my own body and it is no longer obvious that I can trust my body. But being as optimistic as I am, for the sake of convenience I assume that cancer will not strike me twice in a row in such a short time.

A little angel on my shoulder

My optimism bears fruit: the mammogram and the ultrasound show that it is merely a number of cysts. My breast is full of them. Naturally, I'm relieved and I resolve that I will only return to the hospital to work. I feel a bit silly. So much fuss about nothing at all. I must regain confidence in my body. The breast consultant stressed to me that I must certainly sound the alarm if I feel a lump again. It is not certain that every lump is a cyst and it is better to be safe than sorry. She fully understands that the thyroid cancer has made me more fearful. The cysts will be left alone. It is possible that they will burst and disappear by themselves, otherwise they will only be drained if they become too large. Draining them at the moment doesn't make sense because they will just fill up again. This is fine with me! Relieved, we return home to celebrate the birthday of my deceased mother. I did have an angel on my shoulder today.

THE HOME STRETCH

The days leading up to the holidays are always busy. Why that is I don't know, but every year it feels as if there is so much left to do before the end of the year, as if life won't continue after 31 December. School meetings, dinners with people from work, everything is crammed into these last few days. In the run-up to Christmas we receive news that is difficult to deal with. A close family member is told that she has breast cancer, just after I return with good news from the breast clinic. A day later, a much respected colleague of my husband dies unexpectedly. He meant so much to us during a difficult time. Why are so many lovely people dying?

Ambiguous Christmas

Christmas feels noticeably different this year. I would really like to sing in the choir for Christmas. Although my voice is far from normal, I sing along whole-heartily. I'm all set for the final days of this difficult year. I'm going to make a fresh start in 2013! I have arranged with the company doctor that I will slowly start working again from the beginning of January. And we have planned to go out and dance again for the first time on 5 January. I'm really looking forward to that!

Our parakeet Gerritje also brings a lot of joy and with a bit of luck things will be quieter on the health front.

On the other hand, there are many emotions on the horizon. The past year was marked by a lot of pain and grief. Processing the cancer diagnosis, the death of my mother. My father spends Boxing Day with us and because my husband has to work, I spend most of the day alone with him. For the first time we are really together. We talked, cried and shared feelings that we did not share, or had not learned to share in our family. About love, feelings of guilt and sadness, beautiful things and longing. It really means a lot to me. My feelings are ambiguous, but also positive.

Old and new rituals

After the 'ambiguous' Christmas it's full speed ahead to the end of this year. We are all set to put a rotten year behind us and move on: forward! Because although the sharing of feelings and sadness was good, I'm falling back into my old ways. Move on. I have no idea how you should process things, I'd rather not feel them.

I prefer to bury my head in the sand, because I can pretend that all the misery of the past year is over and I'm going forward to a great new year. A year without hospital, just being able to work, to sing and to enjoy my family! My strong, dear husband, my rock in troubled times and my two growing teenagers of whom I am proud. Of course it means fooling yourself a bit, because some things will just go on, even in 2013. My mother is still gone and I will still have to have scans and take medication for the rest of my life, but you know... I'm still here!

Having emotions, experiencing grief – it makes you grow and makes you stronger. At least that is what I have experienced in the past year. But being strong is also sometimes a trap. I often fall for it: pretending that I'm stronger than I am. Because of this, people often don't see how things really are. But to climb mountains you first have to traverse valleys.

5 minutes to 12

As I do every year, I listen to the Top 2000, enthusiastically singing along to the major hits. Together, we are going to make fritters and on the last day of the year I get up early to make stuffed eggs and snacks for the evening while listening to the last 100 songs of the Top 2000. The fireworks are ready to be lit.

Ever since we moved, ten years ago, we celebrate New Year's Eve together without our old neighbours who have become very good friends over the years. The evening begins with a shared meal. Usually, I provide a salad, hors d'oeuvres or tasty satay from the grill. Our friends are also big Top 2000 fans and whilst enjoying a glass of wine and toast we always listen to the radio. The television doesn't go on

until we have sung along to the age-old number one *Bohemian Rhapsody* by Queen with everyone and the clock appears. The countdown can begin. As always, my husband has to go to the toilet at two minutes to twelve and precisely at midnight the champagne cork flies across the room.

Seize the day

This year the champagne corks are the sound of relief. Not only for me but also for my friend who, like me, lost her mother this year. Whatever happened that year, it certainly wasn't only misery. We had a wonderful holiday in Turkey, we went to Disneyland before I fell ill, we lost friends, but certainly made new ones and also rekindled old friendships. If I lost my positivity on occasion, whether or not under the influence of raging hormones, I certainly gained another (perhaps better) perspective on life. Very slowly, I have returned to myself. You should cherish what you love. Carpe Diem – Seize the day – and that day is now 1 January 2013.

NEW ROUND, NEW OPPORTUNITIES

2013! The new year has begun. I have decided to make this year my own! This year we are popping, changing tack. This will mean: no more whining from people who expect everything from you, but don't give anything back! I have had a major clear-out in my circle of friends and acquaintances. Some of them, as we unfortunately saw last year, can only take. While I was ill a lot of things became apparent to me with regard to friendships. I made a number of good resolutions. From now on my family comes first. I plan to exercise more. In any case, we plan to go dancing this weekend. We are really looking forward to that! I am also going to start working again. I want to pick up the thread again. I'm going to turn words into deeds and hop on the bus. Today I'm going to work for a few hours. This afternoon already, to start with, and then after the weekend I want to get up at the same time as my husband and gradually return to my old habit of being on the bus around 7:00 hrs. Instead of only getting dressed at 11:00 hrs. All these plans feel quite good.

Back to work

At work, a huge, warm welcome awaits me. There is a beautiful bouquet of flowers on my desk and a 'welcome back' card is stuck on my PC. What great work colleagues I have. This really makes it easier to come back. All in all, work is very tiring. The commute is especially difficult, but I am satisfied. Next week I want to try to work three hours a day for three days.

Full of energy

Over the weekend I'm still full of energy. Where did this suddenly come from? I decide to take advantage of it and go walking on the dike with the neighbour. A seven kilometre route. The cup of coffee when we returned was really well-deserved. Back home I cheerfully start clean-

ing up the Christmas stuff. I realise that we have more Christmas items than I thought. And that is leaving the tree and Christmas village where they were. I love having a little space in the house again. But secretly I'll miss the cosy Christmas lights. After cleaning up I'm going to get ready for the evening. We're going out again for the first time in ages. A dance party with 70s/80s music for people over 30. I'm curious. This will be the first time that we're going to this monthly party. My husband is afraid that he is going to an old-persons home for over-30s, but we're really looking forward to it.

Teething problems

We enjoyed the dancing but I am glad that a Sunday follows a Saturday, because it has been quite a week for me. Overall, things are still going well. Getting up early is still something I find difficult. Getting up at 8:30 AM is still too early for me. It feels like the middle of the night. My system is still very confused. Getting started in the morning takes a long time. The plan to get up earlier is off to a good start. But I do notice that I should take it easy. For the time being, it's going to be 9:30 AM or even 10 o'clock.

Clearly I'm having problems getting started. But that's okay, because I've have come so far in roughly a month. Not every engine runs smoothly right away. Sometimes you need a lick of oil. In my case that's T4-thyroid hormone.

THE BRICK WALL

Of course it was inevitable. There it was then: I hit the wall. I did too much at work. A somewhat longer day of two and a half hours with a one and a half hour meeting seems to have been too much. Today, my day started really badly. The good thing is: I was able to get out of bed by nine o'clock. It sounds strange, but I'm really proud of that. The rest of the day was rather rough. Every single step drained me of energy. I cannot begin to explain how tired I feel. I'm curious to see how things will go when I start working three hours a day for three days. Realistically, I don't think I have it in me. But we'll just have to try. If it works, so be it, otherwise I'll just have to take a few steps back!

Where there's a will...

In between work, we've booked our summer holiday. It's still early, but we are already looking forward to it. We're going back to Turkey again – it really worked out well last year. Sun, sea, beach. I've also made an appointment to do exercise under the supervision of a physiotherapist. The physiotherapist has explained everything to me. It sounds very positive. I just need a referral letter from the GP and I must call my insurer.

The intention is to first perform exercise one-on-one with a therapist who specialises in cancer patients. She will then draw up an initial customised exercise plan and after that I will exercise in a small group (up to ten people) under the supervision of a physiotherapist. Every week, they will check whether the pace can be picked up to increase the level of exertion.

At the moment I am literally frozen up, so I'll be glad if my muscles become suppler. Getting into shape will also be very welcome. Climbing stairs already feels like climbing a mountain. In any case the will is there!

Progress is being made

Although it's difficult, it's wonderful to be back at work. The downside is that I'm shattered by the time I get home, where there is still household chores to do. My muscles are frozen and I'm dead tired. After the first week of three hours a day for three days I must honestly say it's the most I can do for now. Maybe even a bit beyond my capabilities.

But I don't intend throwing in the towel, so we're just going to keep trying. I'm busy getting my life back together and that feels good!

Better

Clearly, the thyroid hormone is beginning to kick in a bit. This is readily apparent from my bowel movements. For a week or two I've been able to go to the toilet nearly every morning. I haven't been able to do that for years, so it's a whole new experience. As strange as it may sound, I'm ecstatic on the toilet every day.

I still do a lot of walking. On the dike with the neighbour or in the forest with a friend and her dogs. All in all: it is getting better. Slowly, but surely! What a wonderful thing to be able to say that.

STRANGE THOUGHTS

In the meanwhile, the referral letter to exercise under the supervision of a physiotherapist has arrived. The GP really welcomes the plan. I am going to make an appointment for a first time. I hope that a spot is available soon. Anke is on the move!

Once a year I have to make an appointment with the GP to check my sugar because two years back I had pre-diabetes. The sugar level was excellent: a value of 5.8. So I only have to go back in a year. That too is going in the right direction!

Strange talk

That I shouldn't have said that out loud becomes apparent a few days later when I wake up. I feel strange. Clearly, something's not right. Just like every other morning I wake up because my husband has to go to work early. And just like every other morning I ask him whether he wants to set the alarm. It must have sounded like gibberish. No matter how hard I tried I couldn't say the words. My husband, who knows what I mean, doesn't notice anything. I tend to mumble a bit early in the morning, he told me later. Apparently, he thought I wasn't completely awake yet.

After he left, I felt my mouth and noticed that one side was drooping. It feels a bit like it has been heavily sedated, like when you go to the dentist to have a tooth extracted. I realise that I need to take my thyroid hormone, but the water dribbles out my mouth again and runs down my chin. I feel awfully tired, and finally fall back to sleep. When I wake up a few hours later my mouth has straightened itself out again. For safety's sake I report this strange event to the GP, but I expect it has something to do with the residual symptoms caused by the missing thyroid gland. My muscles are also having start-up problems and my toes and fingers often refuse to cooperate in the morning, so why not my mouth as well. However, somewhere in the back of my

head I have the feeling that it was rather strange and that this odd phenomenon could well have been a TIA (transient ischemic attack) or a mild stroke.

Despite the alarm bells ringing in my head, I decide not to be too concerned about it. I let it run its course. The symptoms are gone, aren't they?

The company doctor

I continue having a lot of problems with getting started and the days are difficult. I do everything that I have to, but my heart isn't in it. The days on which I go to work are tiring, but I persist, despite the fact that I think: 'you're crazy not to just go home.' I really need my days off to recover again. I notice that I have a lot of difficulty concentrating. I have to write the smallest details down and if I have more than two tasks to do, I become confused. I find that this is making me very grumpy.

The company doctor is also of the opinion that it doesn't make sense to extend my working hours at this stage. I will first have to feel a difference. No longer having to take a day to recover after working for a few hours. We'll review things in a week or two. The idea is to slowly attempt an increase again after these two weeks. I only have to come back in a month. I feel understood and that brings relief. The company doctor does advise me to make an appointment with the company social worker. I have an impediment because of the limitations I have and I must learn to deal with it. Perhaps he has a few tools to pave the way back to normal life. I grab every possible opportunity to revert to my old, normal pattern, so I schedule an appointment for the following week.

A YEAR WISER

Between recovering and the strange thoughts I have a birthday. This year, having a birthday causes mixed emotions. My first birthday without my mother. If the phone rang in the morning, she was the first one to call. I miss that. Despite the emptiness, I'm really looking forward to celebrating my birthday. Perhaps that's because I'm looking at things differently now. I'm glad I have something to celebrate! However much I miss my mother, life goes on and I'm still here!

World Cancer Day

I decide to celebrate my forty-first birthday in grand style. Entertaining friends and family, but first I'm going to the open day the hospital has organised for the occasion of World Cancer day. I'm going with my ex-sister-in-law, who has breast cancer. We really don't know what to expect, but it turns out to be an excellent day. Very tiring, but very fulfilling and very pleasant. There are more than 3000 visitors. There are over 40 stands spread around the hospital and we can visit them for quite a few demonstrations and workshops. An excellent day with a tremendous amount of information about cancer.

We are very spoilt with make-up, a rose, chocolates and many other things. We were given a tour of the operating theatre and saw a robot surgeon in operation. At the Thyroid Foundation stand I was able to obtain all sorts of information about thyroid cancer and I bumped into my endocrinologist there, with whom I had a straightforward chat. This made the distance between patient and doctor a lot smaller without the pressure of the next patient waiting in the waiting room, which was very pleasant. We went home feeling good. My sister-in-law stayed and had a meal with us before returning home very tired.

That same evening I celebrated my birthday. Very special; I've been very spoiled. The next day, the wall was there again, which was unavoidable, but it was really worth it!

Fright

I ran into the wall, but so too did my son... Early the next day I received a telephone call telling me that he's been hit by a car. Because my muscles won't work, I can't answer the telephone quickly enough and because of that I miss the telephone call. Unknown number, so I can't call back. Because it's so early I just know that something is wrong. Another call comes in quickly. Fortunately, my son is doing well. I'm relieved. His bike is broken, as is his finger. But it's still a scary thing. I let my work know that I won't be going in today. My shoulders are really tense. Because I woke up so suddenly and got up so fast, my body doesn't want to cooperate. So today really is an off-day. It feels good to pause anyway, because I notice I've been having a lot of difficulty with fatigue. Constantly having to explain to others how tired I am wears me down. I decide to focus on my son and put myself in relax mode.

Ring

The phone rings in the afternoon. It was the company social worker cancelling. The next available appointment is three weeks away. I notice that it irritates me. There are a few rather urgent things – things that need to be discussed! But of course I don't say that. In a case like this my nature is against me. By nature I'm a positive, cheerful, up-and-at-it, seize the day type of person, but sometimes that is a drawback. If you're constantly laughing you don't come across as credible when you're at your limit, like now. Right now I'm also paying for the fact that I continued pushing on with insufficient energy. Physically, things are just bad. I'm tired, my body hurts, my concentration is below zero, and I can hardly explain all the things that are difficult to do, which would normally be a matter of just getting on with it. On occasion, I look like a very old woman! And at 41 I'm entitled to say that I'm still a spring chicken... Right?

OPEN LINES OF COMMUNICATION

Because I was not happy with the company social worker calling to cancel, I reported this back to the company doctor and the social worker. I must learn to say honestly that things are not going as well as I make it seem to be. I'm always inclined to play down how I feel. And then push myself beyond my limits. I should have said immediately that the three-week delay is far too long. Talk about building up tension.

In addition, I spoke to a resident neurologist who is a friend of mine about the last incident with my drooping mouth and strange speech. He thought it would be wise for me to ask for a referral to a neurologist. I'm still having doubts about it because it was quite a while ago and nothing happened after that. Honestly, with all that is going on I'm starting to think that I'm becoming a hypochondriac.

Carnival time!

The time has come for some fun and as an old Brabant girl I would really like to go to an old-fashioned carnival again. Whether I'll be able to do so with all the fatigue and muscle pain is the question, but I just want to have some fun, get out and about and LIVE! So dressed up in a baker's outfit, my husband, our best friend and I wade into the revelry. CARNIVAL TIME!

The company social worker

The company doctor quickly responded to my mail about the rescheduled appointment with the company social worker and invited me for a discussion. The discussion comprises a torrent of emotion and frustration. It was clearly urgent to get it out, because now everything came out.

About how people ask me how it's going and I always laugh and say 'fine'. How I am impeding myself, how much anxiety there is about being on disability benefits after already having been on benefits for

ten years in the past, when I was suffering from whiplash. Returning to work was difficult. How I am starting to feel like a hypochondriac every time something happens like it did with the possible TIA. How insecure I become about the looks and comments from people around me, how bad I want to do things but can't do them. How I miss my mother, how I haven't been able to give everything a place yet because I'm busy pushing on and surviving instead of processing things. Everything! A day later I'm able to visit the company social worker. I'm very relieved. In a week or two we are going to see whether I can increase my working hours, but not sooner. That's reassuring. In any case I'm going to take one day off work because my husband is taking me to a Peter Pan show. I was given tickets for my birthday on Valentine's Day. Speaking of romance. I love the story of Peter Pan. In any case, I'm a big Disney fan, but Neverland, Peter Pan, and the headstrong fairy Tinkerbell have a special place in my heart.

The visit to the social worker goes well. Although very intense and emotional. I become particularly emotional about the death of my mother. Clearly, I have not processed everything yet. I just never got around to it because I've been busy with pushing on and with my health. A proposal is drawn up for a course and we can get to work.

EXERCISE IS HEALTHY

It's time to follow through on good intentions. I'm going running for the first time today. In conjunction with my husband I'm going to follow a constructive scheme to go running. Another step in the right direction! Meanwhile, ramping up the sport schedule at the physiotherapist is in full swing. And to cap it all my husband and I have signed up with a fitness club to work on getting our bodies in shape.

Exercise is emotional

Exercise seems to work as therapy. Suddenly, somewhere between the cross trainer and abdominal exercises I break down. Floods of tears like the Niagara Falls flow from my eyes. The physiotherapist takes it in her stride. It seems to be a normal phenomenon. After a few weeks she sees most newcomers break down. Anyway, it's a huge relief to me. As if a burden has been taken off my shoulders I start enjoying my exercise and the same evening I go for a run. It goes a lot better than the first time. I can run for two minutes at a time without falling down blue in the face.

Exercise is trial and error

The physiotherapist's training schedule is getting better. Whereas at first I could hardly keep myself upright on the cross trainer for three minutes at a time, I have built this up to ten minutes at a time. Every Saturday I walk to the gym with my neighbour without reluctance. It makes up for the walk on the dike, because now that I'm busy building up my working hours I'm a little pushed for time. The gym is becoming a routine. We know exactly what we have to do. The physiotherapist does her rounds with all participants, asks how it's going and modifies the schedule where necessary. I enjoy it when the bar is set a little higher. I see clear progress. However, I'm not enjoying the running. I have injured my shin and I honestly don't know whether

it's wise to persist with this. Relaxing makes a nice change. After another morning run and an afternoon in the gym a friend and I enjoy a trip to the spa. It's one of my birthday gifts. After an hour my fingers are completely wrinkly. The hot tubs relax every muscle in my body. I'm actually doing the right thing.

Exercising means more energy

I read a quote: 'Becoming healthy is the best decision I have ever taken.' As if that is a choice. But as far as I was in control, when the cancer diagnosis came down on me like an axe, it is a fact that deciding to exercise has been one of the better decisions. Since I started going to the gym and running I have much more energy. Exercising gives me more energy instead of draining me of energy. And that was more than welcome. It's as if I'm developing a kind of addiction between the thyroid hormone and the exercising. I run on those little pills. And that can be taken literally, because last week I heard that I will slowly die if I do not take them. That gave me a bit of a fright. I wasn't aware that these two small tablets, a pink one and a blue one, could be so vitally important.

Aiming at 100

Anyway, it hasn't come to that yet. I plan to live for one hundred years. In the meanwhile, things are going well. There are a few nice things on the horizon. If I keep on building up like this I will be working full time again in a month and a half, according to my calculations. Exercising has rejuvenated my energy and put me on the highway to health!

A FULL AGENDA

My schedule is filling up. Between working, the visits to the company social worker and exercising, appointments with the endocrinologist are also ongoing. For a thyroid cancer patient my blood values are looking good. A TSH below zero, as intended. The endocrinologist has scheduled an ultrasound of my neck for April and is discussing with the nuclear medicine specialist whether this still needs to be done in June because my Tg values are very low. Based on this Tg value they actually consider the cancer as good as cured. A scan would mean, whether or not with injections, that everything would come to a standstill again. It will mean that I need to stop taking thyroid hormones for a while to prepare, which will make me sick again. In addition, I am referred to the neurologist. That means a new appointment added to the agenda. I have been referred because the tingling and paralysis in my arms and fingers might be an indication of carpal tunnel syndrome. This seems to be more common in thyroid patients. I intend raising the issue of the possible TIA seeing that I'm going to the neurologist anyway.

Too full?

Despite the apparent improvement, there is still the occasional dip. Like today. Maybe that's due to the crowded agenda. I notice that being this busy is breaking me down. I have to run all over the place and at the same time start working again. I am no longer able to get any rest. There is virtually no more time for pleasant things, because my days off are filled with things to do. Travelling to and from work on the bus also takes up a lot of energy. At the end of my work week, I'm very tired. Maybe that's a sign that I shouldn't try to add an additional half an hour next week. Today I suddenly blacked out. I simply couldn't remember how to put a call through. With the customer on the line, I just sat star-

ing at the buttons for more than five minutes. That was really weird; I was just completely lost.

At the same time I really don't feel good. My energy level is low, hormonally I feel like an onion, I feel as soft as a marshmallow. Running again this evening and I am dreading it. Also the singing last night was a big disappointment. I was really looking forward to singing my heart out, but practising for Easter is not exactly going all-out. The theme is a bit less cheerful and the emphasis was more on perfecting things than on singing, so there really wasn't an opportunity to sing my heart out. These types of rehearsals are necessary for ultimate success, but I was looking forward to just letting go. I notice that more often than not I give up on things that should relax me. Like I can no longer keep up. Singing is nice, but I'm dead tired before I arrive and by the time I get home I'm really exhausted. No, this is clearly not my week.

Great prospects

I admonish myself. Shoulder to the wheel and push on. My own complaining makes me negative. It also accomplishes nothing. I'll just have to accept that some weeks will be like this and focus on pleasant things. For instance, the children are doing very well at school and in their part-time job at McDonald's, where they've only just started. The trip to Disneyland Paris that I have booked as a surprise for my family to get over the nasty experience of the past year. I'm able to contribute to a project by the Thyroid Foundation: the book *Faces of thyroid cancer* with positive stories about people who have had thyroid cancer just like me. Our Polish exchange student is coming soon and to top it off: a front row ticket to the Barbara Streisand concert that my sister has given me. She has given me a dream. I have been a great fan of Barbra Streisand since I was a little girl. She is my idol. The reason why I started singing. Now she is coming to the Netherlands for the first time, and probably the last time. And I'm going! The three of us are going. My sister, her daughter and I. I still can't believe it!

Another new appointment

Arriving home after work I find two letters from the hospital on the carpet. It's about my visit to the neurologist. In a few days, I can go for the examination regarding carpal tunnel syndrome. It is a rapid diagnosis outpatient clinic, which means that I will undergo all examinations on the same day and possibly be treated with an injection or be given a referral to the surgeon. I'm not too keen on the latter, but if it has to be done I'll just have to bear it.

The second letter is from the Department of Radiology. At the beginning of April I will have an ultrasound of my neck to see whether there are any lumps that don't belong there. To be perfectly honest, I find this more exciting.

CARPAL TUNNEL SYNDROME, NOT A DREAM

Unfortunately, the visit to the neurologist for the rapid diagnosis turns out to be unsatisfactory. Because I don't know what's intended and there is also the issue of injections I would rather not go alone. Fortunately, my neighbour goes with me. That makes the long wait in the empty waiting room a little more pleasant. Weird too. We are in a completely empty waiting-room, but nevertheless we have to wait for an hour. Eventually, I'm called in for an EMG (electromyography) and ultrasound of the nerve. First, my hands are warmed up in a basin of lukewarm water. The functioning of the nerve is measured with small electrical impulses. After that I'm given the ultrasound. The thickness of the nerve in the wrists and forearms is examined. The examination is over in fifteen minutes and is virtually painless. Rather a funny feeling, those minute electrical impulses. After that, I'm sent back to the waiting room again. In the meanwhile, the results are discussed with the neurologist. He then updates me on this. The examination does not show that there is carpal tunnel syndrome. According to the neurologist this is strange, because the symptoms speak for themselves. Because of this result we are first going to try nocturnal splints and if those don't help within 6 to 8 weeks, proceed with injections anyway. I can take the splints with me immediately. On the one hand, I'm enormously relieved, on the other hand, frustrated. Another one of those annoying symptoms with no apparent reason. You almost begin to doubt yourself.

... but a nightmare

Armed with splints on each hand/forearm, I go to bed in good spirits. Tonight I'm going to sleep and dream without difficulty! Unfortunately, I throw the splints down next to the bed within the first half hour. They are terribly irritating. The Velcro sticks to my pillow, nightshirt and hair. When I turn over, I keep hitting my husband on

the head with the splints. They could double as murder weapons. Handy if he snores, but not really useful at the moment. Away with them!

The result is another night of dead hands. Now, I can do one of two things. Wear the splints anyway and not sleep due to the irritation with the added risk of a divorce on grounds of assault, or not wear the splints and have my hands go numb, which they can't do anything about anyway. I'll give it more thought tonight, but I think that the splints are going to be placed on eBay.

Splints for the shins

After a restless night I have a good workout the next morning. I've been looking forward to it. But I'm not enjoying the running. I find it a burden. That is because the last two occasions have been very tough and painful. Especially on the tibia. Nevertheless, I decide to persist. Before the heat wave hits I want to have quite a few kilometres behind me. And anyway, I can always attach the hand splints to my shins.

WHAT A PAIN IN THE NECK

Today, I had my first follow-up ultrasound after my thyroid gland removal. It was a thoroughly unpleasant experience. The lymph nodes in my neck were checked by an ill-mannered pain in the neck who was clearly in need of a course in communication skills. Initially, I was not nervous at all, but this person unsettled me. While messing around with gel on my neck he blithely informed me that some of these lymph nodes were swollen and would have to be examined by the specialist, then he left again as abruptly as he had arrived.

The clumps of gel were still hanging from my neck. This was a very quick, surreal first encounter regarding what can best be described as a very serious subject. I was left with questions.

After this unpleasant visit I went to the Endocrinology outpatient's clinic. At the beginning of April I have a telephone appointment with the endocrinologist. But I am not too worried, because swollen lymph nodes can mean anything, but it changes my perspective on whether or not to have that scan. If the slightest doubt exists about these lymph nodes, I want the scan. Better safe than sorry. My blood results often indicate something other than intended.

I sang too hard

There are occasional signs that make me fear developing cancer again. These need only be very minor things, even if it is just irritation of the scar. Nevertheless, I laugh off these fears. The blood results are always good, I feel better, have more energy. So nothing to worry about! That was also my frame of mind going for that follow-up ultrasound. No worries.

Until that pain in the neck started mentioning swollen lymph nodes, refused to answer questions and provided no clarity on when and from whom I will receive a result.

For the first few hours I jokingly said that I'd simply sung too hard yesterday and that made the lymph nodes swell up, but secretly I was fearful.

All of a sudden, my thoughts return to that rotten cancer. And while I am busy reassuring myself, the program 'A new beginning' starts on RTL4. A thyroid cancer patient literally tells my story. How I feel deep down inside. How I feel when I stand in front of the mirror, having gained pounds and have the self-image of an elephant – enormously confrontational.

Telephone

Unfortunately, the telephone call from the endocrinologist doesn't set my mind at rest. There is a swelling in the lymph node, but for now we are going to presume a cold. This can cause a swollen lymph node. I don't have to be concerned about it. A cold? I really don't have a cold! Have also not had one recently.

The uneasy feeling from last year is back again. It started last year with the sentence: 'Madam, you have cancer, but it is so small we are going to leave it alone and see what happens.' Now a year later after the first follow-up ultrasound: 'Thyroid cancer metastases are seldom found in a swollen lymph node like the one you have, so we will take another look in a year.' The ease with which my sense of disquiet is swept off the table, in any event that's how I feel about it, and the control that I don't have over my body and life make me even more restless and uncertain. And if I express my feelings out loud, I feel like I'm pretending, because the doctor can't see any reason for alarm. I must communicate the feeling that this gives me in a better way. He can, after all, not see what's going on inside me from the outside. In other words, if the doctor does not know that I am so worried, I'll just have to wait. And I don't want to wait. Again, this shows how important it is to make it clear to the doctor how I feel, what symptoms I have.

This illness has quite an impact. This thyroid really is a pain in the neck!

ALL'S WELL THAT ENDS WELL

After the dubious result of the ultrasound and the call from the endocrinologist that didn't reassure me, I decided my communications with the endocrinologist must be clearer. In the past year it has become apparent how important communication between patient and doctor is. If I was not clear at the outset about my feeling and about what I did and did not want, the thyroid would've remained in place and the cancer would have still been in my body. I don't want any more ambiguity, no sense of disquiet. The doctors work with tangible facts. On scientific evidence, blood results and established guidelines. The patient, and then naturally I am speaking of myself, proceeds on the basis of emotion! It is very important to convey that emotion to your doctor. Everything stands or falls with good communication.

It's all about communication

I contact my treating physician and explain my fear. I certainly don't doubt my doctor's expertise, but I'm worried. That's how I feel. This form of open communication gives rise to mutual respect and understanding. Communication with your doctor should be something everyone has access to. Especially for a disease where you know in advance that you are going to spend quite a lot of time with each other. Being listened to in itself brings reassurance. The doctor decides to take another look at this year's ultrasound and to compare it to last year's ultrasound.

Free

On 12th April 2012 – nearly a year after the thyroid cancer diagnosis – I'm again sitting in the endocrinologist's office. I'm nervous. I just want the cancer to be over. Continue to recover, get better and start living my life again. The endocrinologist quickly alleviates my suffering. It turns out that last year's ultrasound already showed a swelling in the

same lymph node. The lymph node has not grown in the last year. In other words it is very unlikely there can have been any metastasis. I will have a follow-up ultrasound every year, but aside from the virtually immeasurable Tg value I can actually say that I'm now 'FREE' of cancer.

A huge wave of relief washes over me. Not only over me, but also over my husband and my two sons. We are about to close the door on a very difficult period. A year of illness, loss, pain, sadness, and fighting. We show the fear and the uncertainty the door and we go on. Perhaps without a thyroid gland, but with a lot of wisdom that we have gained over the past year and an extra dose of lust for life.

12 April 2013

AFTERWORD

A YEAR LATER

In retrospect 2013 was indeed my year! The strange thought that I woke up with one morning indeed appears to have been a mild stroke. The symptoms I still have like headaches, forgetting how to put a telephone call through and the impaired concentration most probably derive from that. Yet it remains debatable, because impaired concentration and forgetfulness are also common residual symptoms of thyroid disease. Time will tell. Sometimes you simply don't know the precise underlying cause for a specific symptom. The main thing is that you learn to deal with it, to live in the present and to enjoy all the good things, however small! Meanwhile, I'm regaining my footing. All the good prospects I had for 2013 were, in a word, unforgettable.

After I turned my back on thyroid cancer this year with the happy news 'you are free' I'm going to carry out the intentions that I had during my period of illness. I'm going to work for thyroid cancer patients who are, just like I was, in search of recognition and understanding in a tangle of emotions, fear and uncertainty that descends on you when you are diagnosed with cancer.

In mid-2013 the book *Faces of thyroid cancer* was published, in which eighteen thyroid cancer patients collaborated. A great, positive project by SON (Dutch Thyroid Association), in conjunction with Genzyme, that uses encouraging tips, quotes and beautiful pictures to uplift and support patients who have been diagnosed with thyroid cancer. I'm proud to have participated as one of the faces and I had the honour of handing the book over to endocrinologists Prof. J. Smit and Dr R. Netea-Maier at a thyroid symposium in the Radboud University Medical Center of Nijmegen.

In the autumn of 2013 I had the honour of firing the starting pistol for the thyroid cancer run in Leiden during the annual ETA (European Thyroid Association) congress that took place in the Netherlands in 2013. I became active on the pages of fellow sufferers and because of all the recognizable things that I read there, I decided to convert the diary that I kept during my illness into a weekly column on the website of SON. I wanted to share my story, with the goal of offering recognition and giving a voice to thyroid cancer. Many patients have expressed their need for stories of fellow sufferers after their diagnosis. There are only a few about thyroid cancer. That's a pity, because many thyroid cancer patients feel misunderstood and caught up in a chronic disease. For many people, life without a thyroid gland means taking thyroid hormones for life. Symptoms such as fatigue, depression, muscle and joint pains, constipation, temperature regulation problems, hair loss, dry skin, flaking nails and hormonal fluctuations are of the order of the day. The lack of attention feels like there is something missing for a large group of patients who, just like me, have been told: 'You're lucky! Of all cancers, this is the best one to have. The 10 year survival prognosis is 90%, it grows slowly and is easily treated. You have the 'Good cancer'.'

Of course, my story is not necessarily typical for every thyroid cancer patient. I know that there are also thyroid cancer patients who are in the fortunate position of having no, or hardly any, difficulty with the symptoms that I have described. That's how it is with every disease. Every experience is unique. This is my story. My only hope is that my story will offer recognition to those who need it. That it will be a light on the horizon that things will improve again, despite any residual symptoms and uncertainties.

That thyroid cancer is a 'good' type of cancer, 'a blessing in disguise' is a supposition that many fellow sufferers have to deal with. While writing my columns I received experiences from readers on a weekly basis, like the following:

Just like you, I've heard the same remarks about 'good cancer' and so on and that I really should not be worried. But this is really difficult!!!

My story is not an isolated one. Hundreds have received the same response to their diagnosis. With this book, I want to open this to discussion.

To provide an answer to the question: 'Good cancer, does it exist?' I hope this book has answered that. My conclusion is ... 'There is NO SUCH THING as good cancer!'

WITH THANKS TO

The most difficult part of writing a book is the last few pages. Who would you like to thank and for what?

Of course, I would like to thank my family, friends, colleagues, the choir in which I no longer sing but in which I was very active at the time and anyone who I've forgotten because I'm currently so forgetful, but there are also a few people who deserve a special place in this book.

In the first place, the three men in my life. *Marco* my dearest, who was been my biggest supporter for nearly 25 years, my rock in troubled waters: The wind beneath my wings.

Our greatest pride, our twin sons *Rick* and *Thom*, who still have a great future ahead of them. Like my parakeets *Gerrit* and *Pukkie*, I want to mention the three of them by name. They have given me much love, laughter and relaxation.

Both my general practitioners who were alert to the fact that something more was going on, made enquiries, investigated further and are very good listeners. The medical staff and the nurses in the short-stay unit and of course my fellow choir member who rearranged her schedule to care for me in the recovery room.

The surgeon, the endocrinologist and the nuclear medicine specialist who have used their expertise to make me cancer-free to this day. Despite confusion, uncertainty and doubt we were jointly able to achieve a good result with open communication. We commenced the 'the patient as partner' development and hopefully this will persist because good mutual communication ensures better understanding of each other. The patient has a story to tell that is worth listening to. The nursing consultant plays a very important role in this. This position makes communication easily accessible.

The exercise physiotherapists who have gotten me to the point of actually enjoying exercise! And believe me that is not easy.

The SON and the Web editor of the SON for the opportunity to convert my diary into a weekly column on their website. Even editing things in the middle of the night so that the Wednesday edition can go out. Who never grumbled when I wanted to change things at the last minute. The feedback, support and confidence they have given me.

My fellow sufferers, thyroid patients both with and without thyroid cancer and other digital friends on a forum where my book actually started, who have supported, read, tweeted and above all understood me.

Loyal twitter followers and followers of my blogs. People who I've come to know on social media, some of them who have even become friends. Without naming names, you know who I mean!

The photographers for their beautiful photos on the front and back of the book (cover photo: Hetty Rommers; back photo: Jacq Roos Photography).

My publisher, who had no doubt.

The director of SON Rietje Meijer who wrote the foreword to my book.

Prof. J. Smit and Dr R. Netea-Maier for their wonderful words in the front of my book and their support during my illness and while writing my book.

My friends who have remained and who have not been scared away by the word cancer, my quirks and the fact that I could no longer go out as much. My walking buddies, the neighbour and my rediscovered friend with the dogs, for the numerous walks over the dike and in the forest where we talked a lot, walked for miles and for the litres of coffee that we drank. The friend who dared to come for coffee after the treatment with radioactive iodine. My old neighbours who have become very good friends with whom we still usher in each New Year and with whom I have shared a wonderful All Souls' Day mass. My neighbours who were there right away when my mother suddenly died, with a shoulder to lean on and a Chinese meal. They are always there for us. Not to mention my very best friend, for 25 years, who didn't even leave after my metamorphosis from The Grudge to Vamp.

COMMENTS

T. de Kruijff: Indeed, good cancer doesn't exist. How admirable of you that it has made you so strong and determined to draw attention to this. Living with chronic symptoms is very difficult, especially if those around you can't see or understand these. Your book is a step in the right direction of awareness.

M. van Schuppen: we virtually walked the same road, at the same time. Often with similar feelings, experiences and problems (or minor problems!). From a similar situation; both mother, partner and employee. Now with residual symptoms, but still with ambitions – that turn out to be more difficult to achieve. I have enjoyed reading her columns, with recognition, every now and then a tear, especially a lot of smiles. I am 'co-proud' of what she has done in this way!!

Dutch Cancer Society: Your story about 'good cancer' is recognizable. In the Netherlands, we are usually happy about having increasingly better chances of survival after cancer, but the long-term consequences, particularly on the quality of life, are not always that great.



Sometimes, you are dumbstruck by the nonsense that people come up with. Is it out of stupidity, ignorance or simply because they don't know how to express themselves when it comes to a disease like cancer? I tell myself that it is well-intentioned, but I'm still left with a gnawing feeling. 'Luckily you have good cancer' still echoes in my head. Good cancer? Does it really exist?

Anke van Haften was diagnosed with thyroid cancer in April 2012. In 2013, she collaborated on the book *Faces of thyroid cancer* and she fired the starting gun for the thyroid cancer awareness run in Leiden.

After her diagnosis, she kept a diary for a year. From January 2014 this diary was published in a weekly column on the website of SON (Dutch Thyroid Association). These columns have now been bundled together in this book, telling a true, sometimes painful, but always humorous story of her experiences over the course of a year. Many thyroid cancer patients will recognise themselves in these stories.

'The book is (...) not only a great comfort to all patients with thyroid cancer, but should also be a required reading for all physicians who still have the concept of 'good cancer' in their vocabulary and actually for anyone who is concerned about the people around them.'

Prof. dr. J.W.A. (Jan) Smit, internist-endocrinologist
Head of the Department of Internal Medicine,
Radboud University Medical Centre of Nijmegen