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andrea pamparana | antonio bianchi

my friend NET

preface by alfredo pontecorvi



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## preface | by alfredo pontecorvi\*

It's like the beginning of a journey. A sudden, unexpected departure. Here it comes, the peremptory order: you must leave, you must get moving, you must face bumpy roads ahead, sleepless nights, overlapping thoughts, ancestral fears emerging from deep within you and clashing with your everyday routine, which is turned upside down all of a sudden, just like this, overnight.

It's the beginning of a new lifestyle: the fight against the evil disease that may take you away forever. Cancer.

The journey, throughout the route that gives a new shape to our daily routine, redefines priorities, encounters, bonds, needs and pastimes in a new order. It moves forward to discover new dimensions. The very ideas of happiness, love, passion, dream and hope break up into a thousand facets. They change us, they reshape our everyday habits, they enhance the power of our gaze, they add a new weight to our words.

This experience turns despair into hope little by little, we regain strength and keep going: there is light at the end of the tunnel.

So, just like this, a slow-paced life begins, where every single moment is marked and weighed up, and that's when

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the disease becomes, almost paradoxically, a friend you are forced to come to terms with, by creating an unspoken, grim, deep coexistence. It is inside us, the disease, we feel its dangerous progression, we sense its deadly power and, nevertheless, we learn to confront it little by little, not to surrender to it, to seek dialogue with it, a suitable coexistence, however difficult it may seem. So this relationship, which was born unexpectedly under difficult and hostile circumstances, becomes emotion, turns into friendship, into a source of comfort, into a place where to take shelter.

Andrea Pamparana, a big name in TV journalism, made that journey and now he tells us about his experience in a book where the disease turns into a challenge, and then into a successful act of love towards life itself.

It took him willpower, perseverance and a keen mind, not to mention a bit of good luck, in order to cope with a journey bristling with difficulties, sharp fragments of pain and inner fear. However, Pamparana's journey reached its end, his eyes bright with emotion and achievement.

Andrea succeeded in communicating with Evil. He welcomed and confronted it on equal terms. He adjusted his psychology and his inner speech. He loved insatiably those who stood by his side and took care of him, thus keeping hope alive.

Many people relied on the written word to describe their experience of the disease, but here the author delivers an unusual approach to this deep and difficult relationship: the disease turns into a friend you learn to live with, by making up a language that develops into an endless arabesque of emotions.

Technology helps us, rescues us and, today, often wins.

The Gemelli University Hospital features the ART Centre, a state-of-the-art department where future is in the air when it

comes to treat illness. Cutting-edge and innovative technologies thanks to which the patients themselves get in the control room of these prodigious machines and aim the radiation beam against the tumour. A shot aimed at the target with micron precision kills the tumour cells with radiation, together with the positivity boost brought about by this kind of approach.

The patient is no longer a passive witness to the therapy, but plays instead the leading role in the fight against cancer. And that is the moment when the fight itself is enhanced by a new presence, by a new awareness that turns into a therapeutic aid. Even statistics delivers us an optimistic embrace: today Evil is confronted and defeated more successfully, or at least its final outcome is postponed.

“Targeted therapy”, or personalized therapy: every type of cancer, and every patient who is diagnosed with cancer, has its own therapy. It envelops us in its beneficial healing blanket and allows us to live longer despite the tumour. Therefore, cancer is no more an enemy to root out at all costs, but a part of us to be checked periodically, with which we must coexist, even on friendly terms.

If it’s true, and it is true indeed, that the psychological attitude is an essential element in the Great Fight, and that the brain is meant to produce auxiliary drugs that act jointly to those prescribed by international protocols, then we can claim that Pamparana’s literary effort provides us with, we should say, a significant scientific contribution to the understanding of a shadowy aspect, which is made up of countless facets, and where grey usually prevails over every other colour. It is exactly this friendly vision of a deep emotional approach that manages to discover unhopd-for resources, which can even brush against the shakes of the regained love.

This book is not a painful biographical fragment: it is a sign of hope we should all share, without exception, in a lasting agreement of fight against Evil on all fronts. Pamparana points out his weapons to us and delivers them to us as if it were a civic duty, a lay duty, which is also marked by an invincible confidence in the fight for Life. And he feels he is not fighting alone. We all owe him something when it comes to Beauty and Good in everyone's life.

The pages of his book, which are permeated by straightforward and intense words, allow even us doctors, whose voices are friendly and fully conscious, to better understand the positive mutual understanding that can be established between patient and disease. The coexistence may often be troubled and all-absorbing but, nonetheless, it is more and more successful and shared, to the point that the disease turns into a friend, or better still, into my friend NET.

my friend net



Let's imagine you happen to walk along a pebbly riverbank. To your right the slow flow of the water, to your left a poplar grove, all the trees lined up to form a nearly perfect and regular net. A sense of peace, of order, everything around you seems to be balanced. Then, all of a sudden, you hear the clatter, far-off at first and then closer, of horse hooves, or so you believe. Are the horses on their own? Or is someone going for a ride through the woods? You realize that the river is not so peaceful anymore, but it is rippling with the waves of a stronger current. The perfect symmetry of the poplars is now replaced by brambles and messy ferns.

And here are the horses. They emerge from a path on your left. But... wait a minute... it's unbelievable! They are not horses, but zebras, with their distinctive black-and-white striped coat.

You are astonished, stunned, even scared. How come there are zebras in this place, so pleasant and peaceful until a moment ago, and now so chaotic and disturbing? Then that sound of hoofbeats was not caused by horse hooves at all, but by other animals that shouldn't have been there in the first place.

A neuroendocrine tumour (NET) is just like this. It bursts into your body without notice. Your body is like the poplar grove, with its regular trees and its peaceful river. Then

chaos erupts with its scrubs, its brambles, its invasive underwood and its swollen river among the rocks. And that sound of hoofbeats makes you think of the most predictable animals, the horses. All of a sudden, some of your cells start dividing out of control. The horses are the cancer cells, whichever type of cancer, which bursts into your body in order to dominate you.

But this has nothing to do with horses. That sound of hoofbeats, all those tests you underwent to understand and explain that chaos, actually identifies something similar – we are talking about equines anyway – but completely different nevertheless. Zebras. They shouldn't be there, and yet there they are.

This is the reason why patients who have been diagnosed with (and treated for) a neuroendocrine tumour know zebras. Zebras are the symbol of their disease. Seemingly one thing, but actually another. And finding out that that sound of hoofbeats is warning you about the zebra's arrival may really save your life.

As George Sande said, «I don't believe in evil, but in the extent of one's ignorance».

One day I heard that sound of hoofbeats too. I waited for the horses for a short time, which however seemed endless to me. Then “my” doctors told me, very tactfully and competently: «We have a carcinoid tumour, it's called NET». The zebras. Professor Antonio Bianchi, an endocrinologist, was going to take care of it. Our friendship was born that day and this feeling developed into a close bond also thanks to this book.

Shortly after I had undergone surgery to remove a primary tumour of the ileocaecal region and an intestinal lymph

node metastasis (the following histological examination was carried out with unquestionable expertise by Professor Rindi, pathologist at the Gemelli University Hospital, who was the first to classify the stages of these rare types of tumour), my surgeon, Sergio Alfieri, examined me to check the surgical incision site and told me with his usual frankness: «When I opened you up and decided to perform a laparotomy (the incision into the abdominal cavity) instead of a laparoscopy (minimally invasive surgery performed using three small incisions), I got worried. Thankfully, there was only one metastatic lymph node but, strangely enough, it was the most distant one from the primary tumoral lesion, as confirmed by the histological examination. All in all, your NET is quite a little bastard».

Well, NETs are quite rare, and we will discuss later the statistical data regarding both Italian and world population, so I had already cursed quite a lot, rightfully so, because if it is a rare type you also expect it is still quite unknown, but the fact that it could be classified as “a little bastard” seemed totally unfair to me!

At the beginning, when my friend Bianchi and Giovanni Schinzari, an oncologist and specialist in the treatment of NETs, had still not prescribed me my therapeutic program based on somatostatin analogs once a month (who knows for how many years, hopefully as many as possible, I’ll have to follow this therapy), I was very angry. Angry with my bad luck, with fate, with some saints and even with a couple of friends, who were surely in a hypothetical heaven and seemed to have forgotten about me.

Bianchi, Schinzari and the other doctors at the Gemelli University Hospital definitely tried to reassure me and told me that I had actually been quite lucky because I had had a

comparatively early diagnosis and had been treated almost immediately. Besides, the NET, however rare and, let's say, not so well-known, was nevertheless a carcinoid and not a carcinoma, which is more dangerous. That said, I didn't like the little bastard at all.

In the evenings, around 7 o'clock, when darkness fell on the city and I lay in bed, resting, I was overwhelmed by dark and ill-fated thoughts. I began to identify those minutes as my "NET time". A feeling of heaviness, the need to take stock of my life, as if I hadn't been diagnosed with somatostatin, Gallium-68 PET scans, CAT scans and tumour markers twice a year to monitor the course of the disease, but I had been given six sad months to live instead. I have always firmly believed in the interaction between the psyche and the body, in the power of emotions, in the interference between psychology and clinical medicine. Therefore, I tried to focus on reading and studying in order to distract myself in every possible way from negative thoughts, which were likely (and still are) to help the tumoral cells spread through my organs and cause irreparable damage.

At some point, I began to develop a different strategy against the NET. First of all, I acknowledged it publicly: I've got a NET. It could have been worse, that's for sure. So my life's glass was not fuller (if it ever was full), but at least it was still half full. Somatostatin is not a chemotherapy drug. Actually, there are countless drugs for cancer treatment and many of them are far more exhausting and painful to bear.

There was always the issue of the metastatic lymph node, which was unusually distant from the primary lesion. I figured, and still figure today, that a cell, perhaps only a single cell, a tiny cell, which escaped the surgeon's watchful eyes and hands, as well as the Gallium-68 PET/CT (don't worry, someone

more experienced than me will explain what this test is) or the CAT scan with contrast, was wandering around my body looking for other healthy cells to stir up against me.

And then, how do you confront such a little bastard?

By showing anger? Aggressiveness? I am glad to leave that task to whoever is competent. Antonio Bianchi certainly knows what he is doing. And so does Schinzari. And, should it be necessary, Alfieri and Roberta Menghi, his assistant surgeon, are always ready with their scalpel. No. I chose to play the role of the so-called “clever bastard”, so to speak. I cuddle him, I flatter him, I let him know that I hold him in high regard, that I am even fond of him after all. I hope this sort of love may be returned.

My friend NET.



Women must do breast self-examination regularly and undergo annual clinical tests to monitor the situation and detect potentially dangerous swellings at an early stage. After the age of 50, men must do a blood test to measure their PSA levels and detect possible prostate enlargement. Besides, men and women after the age of 50 must get a colonoscopy to check the intestine. I deliberately wrote “must”, and not “should”, because these routine check-ups can really save your life. Today pap tests among women, or PSA tests among men, have become a routine practice for any conscientious person. «How are you?», «Everything’s fine. I got my PSA results and they are good». Unfortunately, you’ll never hear someone say: «I’m well. I’ve just had a colonoscopy, everything is fine». Do it, just to be on the safe side.

I did have a colonoscopy. I had no other choice unfortunately. And I can assure you I owe a deep debt of gratitude to professor Petruzzello and his team. I had just been admitted to hospital with a painful intestinal colic. At the emergency department, a particularly attentive and conscientious physician, Dr Covino, told me that something was probably wrong with my bowels, an obstruction in all likelihood, and that they had to investigate its origin. I didn’t even know the meaning of the word “NET” at the time. Colonoscopy? Ouch, I guess they are going to insert something

into your rectum, a colonoscope with a camera on the end to be exact. Awkwardness, unease, potential pain. They put me at ease. The procedure is performed under anaesthesia, a quick nap while the exam is underway. In some cases, small tissue samples can be taken as well in order to perform a biopsy.

I'm tense, worried. On the day before the exam, a kind anaesthetist suggested that I should shave completely. I obey, however reluctantly: I have had a beard for fifty years, and I'm rather proud of it. Yes, half a century. It seems that, in case of emergency, anaesthetists prefer a clean-shaven face, so that the beard won't interfere with possible masks or intubations.

I get into the endoscopic procedure room and another anaesthetist, with a long and thick black beard, smiles at me: «Why did you shave off your beard?». I remember my manners and refrain from answering. However, I inwardly deliver a gentle rebuke to his young colleague.

«Now lie down on your side. I'm going to inject the anaesthetic... you should start counting to three and just relax, think of anything beautiful you can come up with».

One, two...

Let me digress a little here. In 2013, I often travelled to Siena because I had been assigned to carry out a report on the financial crisis that had hit Monte dei Paschi di Siena. I immediately fell in love with Simone Martini's hometown. In a matter of just a few months, I was co-opted into one of the seventeen *contrade*, "l'Aquila" ("the Eagle"), by my close friend Franco Moretti, known as the Moor. Since then, I have been a so-called "protector", a fully-fledged member of this noble and ancient *contrada*. I have taken part to all the rituals of this renowned and legendary Palio twice a

year, on 2<sup>nd</sup> July and 16<sup>th</sup> August, since 2013. Unfortunately, the last victory of our *contrada* was back in 1992, when its famous jockey “Aceto” (“Vinegar”) won on Galleggiante (“Floater”).

Now, considering that the anaesthetist had told me to focus on something pleasant, beautiful, positive...

One, two... I fell asleep.

I woke up ten minutes later. A pleasant feeling, as if I had slept for hours. Unfortunately, the image of the jockey, who raises triumphantly the scourge after so many years my *contrada* had been left empty-handed, had disappeared in the anaesthesia tube, just like number three. I remember that the following day I phoned my Prioress, Fiamma Cardini, and told her: «There’s nothing to do Fiamma, we didn’t win, not even yesterday in my dream. I just fell asleep before it could happen».

A few days later, I got the results of my colonoscopy and biopsy. We have a carcinoid, we have a NET. And that acronym came into my life for the first time. A neuroendocrine tumour.

What is this NET I have told you about? And why, according to my surgeon, professor Alfieri, is this type of tumour “quite a little bastard”?

I could tell you so many things about my experience at the Gemelli University Hospital, about the diagnosis and consequent surgery at first, and about somatostatin therapy later. But only a physician, and an endocrinologist in particular, can explain in scientific but understandable terms what we are exactly talking about.

*So, dear Antonio, what is the NET, or rather, as you always point out, a NET?*

The NET, or rather, a NET is the acronym for “neuroendocrine tumour”, which is also called, both in medical journals and treatises, neuroendocrine neoplasia (NEN). Neuroendocrine tumours are a heterogeneous group of neoplasms that originate from neuroendocrine stem cells, which are found in many organs and systems of our organism. More precisely, we could say that the system of neuroendocrine cells consists of three types of anatomical regions: the neurons and fibres of the peripheral nervous system, the so-called paraganglia, that is groups of neuroendocrine cells that go along the spinal cord from the base of the skull down to the coccyx; the neuroendocrine cells that are dispersed throughout the mucous membrane of the hollow abdominal viscera, such as the digestive tract, the respiratory system, the genitourinary tract, but also the cells located in the skin, in the thyroid, in the thymus, or in the islets of Langerhans in the pancreas; the endocrine cells that form the endocrine organs, such as the pituitary, the adrenal medulla and parathyroid glands.

Before explaining what a neuroendocrine cell is, we need to know what a hormone is. A hormone (from the Greek “ὁρμῶν”, “setting in motion”; it is therefore a sort of “chemical messenger”) is a substance, generally a protein, produced by an endocrine gland (endocrine means “producing and secreting hormones into the blood”) which is released into the blood, thus triggering functional responses into specific target cells located at a considerable distance from the secreting gland. In order to carry out their functions, hormones, after being produced and secreted, enter the circulatory system and reach their target tissues, where the receptors (spe-