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WORDS MATTER

An eMoTioNaL DiCtioNaRY

A GUIDE TO THE KEY WORDS IN ONCOLOGY

«In no other biological science - noted Luca Serianni, one of the greatest scholars of the Italian language - words have been as important as in medicine».
This is even more true in the situation we are experiencing today.
Scientific research progress, prevention effectiveness and the success of therapies make it all the more urgent to definitively overcome the «initial detachment» with which for centuries the figure of the doctor, protected by its «impenetrable terms» (these again are the words of Serianni), was pleased to stand out from common people.

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Concept/Design and realization by
Pro Format Comunicazione

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iNtRodUcTioN

Giuseppe Antonelli and Giacomo Micheletti

«For the last seven months I have kept a secret». Thus began, at the beginning of January 2021, a long post on the social network Instagram: a letter in which Teresa, 22, told the story of her illness. Teresa, however, is the daughter of a very famous Italian singer: Lorenzo Cherubini, aka Jovanotti. So her words spread quickly over the net, end up in the newspapers, are commented on, shared and appreciated. Yes, appreciated, because Teresa has been able to find the right words to say something that too often people prefer to stay silent about.

TALKING ABOUT DISEASE

Her letter is symbolic in many ways. First of all because she decides to break what is initially called a «secret» and to share her own story. Teresa instead openly mentions it: she speaks precisely of a «tumor of the lymphatic system», alternating medical technical words («I was diagnosed with Hodgkin's lymphoma») with words that represent the experience of every person facing such a situation, such as anxiety and fear («after months of anxieties and fear the story is over», «fear has not gone away, and it will take time for me to trust my body again, but I can't wait to get back to my life»).

In telling that story, on the other hand, the letter uses all the words that mark the stages of this kind of experience. The diagnosis: namely the moment of discovery; etymologically speaking it means recognition, knowledge (from the ancient Greek root word *gignosco* «I acquire knowledge, I know»). Then, the almost unpronounceable word: cancer. After that, the therapy: «I did 6 rounds of chemotherapy», «the chemo did not make my hair fall out completely». Finally, in this successful case, the most longed for word, the one that announces healing: «since yesterday, January 12, 2021, I am officially cured».

Even though the most important word is another, and it is no coincidence that in the letter it recurs more than once, and this word is treatment: «a treatment plan», «people at IEO treated me well». After all, it is precisely what is referred to as therapeutic alliance that is evoked. An alliance not only referred to the doctor-patient relationship, but to the surrounding environment in its totality: «I have been incredibly blessed - writes Teresa - to have an amazing family, friends and a fantastic team of doctors that have followed and helped me through all these months». And, after thanking everyone, she concludes: «To some extent cancer is a very lonely disease, but the support of the people around you is crucial to overcome it, I would not have made it without them».

This can certainly be a good starting point for our reflection.

AN INITIAL DETACHMENT DUE TO WORDS THAT ARE NOT EASY TO UNDERSTAND

«In no other biological science - noted Luca Serianni, one of the greatest scholars of the Italian language - words have been as important as in medicine». This is even more true in the situation we are experiencing today. The progress of scientific research, the effectiveness of prevention and the success of therapies make it all the more urgent to definitively overcome the «initial detachment» with which for centuries the figure of the doctor, protected by its «impenetrable terms» (these again are the words of Serianni), was pleased to stand out from common people. If in the past the obscure technicalities of medical language could represent a source of prestige (and awe) among at least some of the public, the renewed attention given in recent years to the linguistic dimension of the treatment process and to the communication dynamics of the doctor-patient relationship calls the entire scientific community to deeply reflect on the key words of this relationship. Because, as it has now been amply demonstrated, mutual terminological misunderstandings can have a negative impact on the therapy.

A SHARED LANGUAGE FOR A TRUE THERAPEUTIC ALLIANCE

In the setting of oncological diseases, the problem of adopting a shared vocabulary is crucial. It is not only a matter of transmitting diagnostic and therapeutic information with clarity and precision, but also - and above all - of understanding the patient's emotional investment. Starting from an experience often marked by fear, by a sense of abandonment and helplessness, the patient feels first-hand the impact of those specialized terms that the healthcare provider uses in a detached and objective manner. This is the reason why a dialogue based on the recognition of the person and his/her emotions - a respectful and inclusive dialogue, able to go beyond the coldness of technicalities and taboos - can be considered a first form of treatment. Certainly not the least effective.

For a long time, tumor (or cancer) has been at the center of a negative culture that even now tends to put pressure on the inability to name the disease itself. It is therefore necessary to learn how to rethink the entire language underlying the relationship between the doctor and the cancer patient. To act on certain obscure and disturbing terms, correct their ambiguities, review their image in the direction of a strong and solid therapeutic alliance. A common reality based on mutual listening and care in its broadest sense: the gradual construction of a new balance. Physical, psychological, emotional. A renewed willingness to accept and accept ourselves.

THE WORDS, THE EMOTIONS, THE CARE

As reported in *Manuale per la comunicazione oncologica (Handbook on communication in oncology)* by Stefano Vella and Francesco De Lorenzo, «an appropriate information contributes to treatment success and at the same time also benefits the doctors, because it enables them to establish a relationship based on trust with the patient that improves and facilitates their professional performance preventing them from falling into defensive medical behaviors». This is because it encourages the patient to actively participate in the therapeutic plans proposed by the doctor, which are then perceived as shared choices, and allows him/her to ask for clarification, share doubts and feelings, and report side effects thus ensuring the customization of therapies.

These are the premises of our attempt to define in this small dictionary a common vocabulary to be regarded as a meeting point between the doctor’s technical language and the highly emotional narrative that characterizes each patient’s experience. The statements collected and discussed in this small emotional dictionary invite doctors - and more broadly the entire healthcare staff - to critically question themselves about some decisive moments during cancer care. The communication of delicate news, not necessarily bad news. The consideration in dealing with the suffering of their patients. The importance of giving a name to things, without convenient camouflage or embarrassment, as the first step to a serene acceptance of the disease and the proposed therapies. Also in this context, as Rosa Revellino noted, we can find words that «on one hand contain and stem the painful experience, on the other they mitigate and lighten up the pain on two different levels: semantically and globally».

A DIFFICULT TIME

Covid-19, as we have all by now learned to call the infectious disease caused by the sudden and striking worldwide spread of the Sars-Cov-2 virus, represents a particularly insidious threat for cancer patients (and, more broadly, for people with serious diseases). First of all because of the possible complications deriving, in case of infection, from one’s own condition, but also because of the effects of the severe limitations due to the pandemic: the rescheduling of urgent examinations and check-ups, the fear of going to hospital, the inability to meet and communicate freely with family, friends and doctors.

As illustrated in *Ancora qui (Still here)*, the short film by Manuel Peluso on the difficulties of cancer patients during the pandemic, the fundamental preventive measures imposed by the health emergency - physical distancing, the use of masks - also could hinder that feeling of empathy necessary to build an effective treatment path: the ordeal of distance, isolation, absence of words experienced by both patients (and their families) and healthcare personnel.

Our small dictionary, that at the design phase was strongly affected by the difficulties imposed by the pandemic, aims to be an invitation to start giving again meaning to words. Even more in this dramatic situation that has almost led us, at least for a moment, to lose confidence in words and in their communicative, relational and healing power.

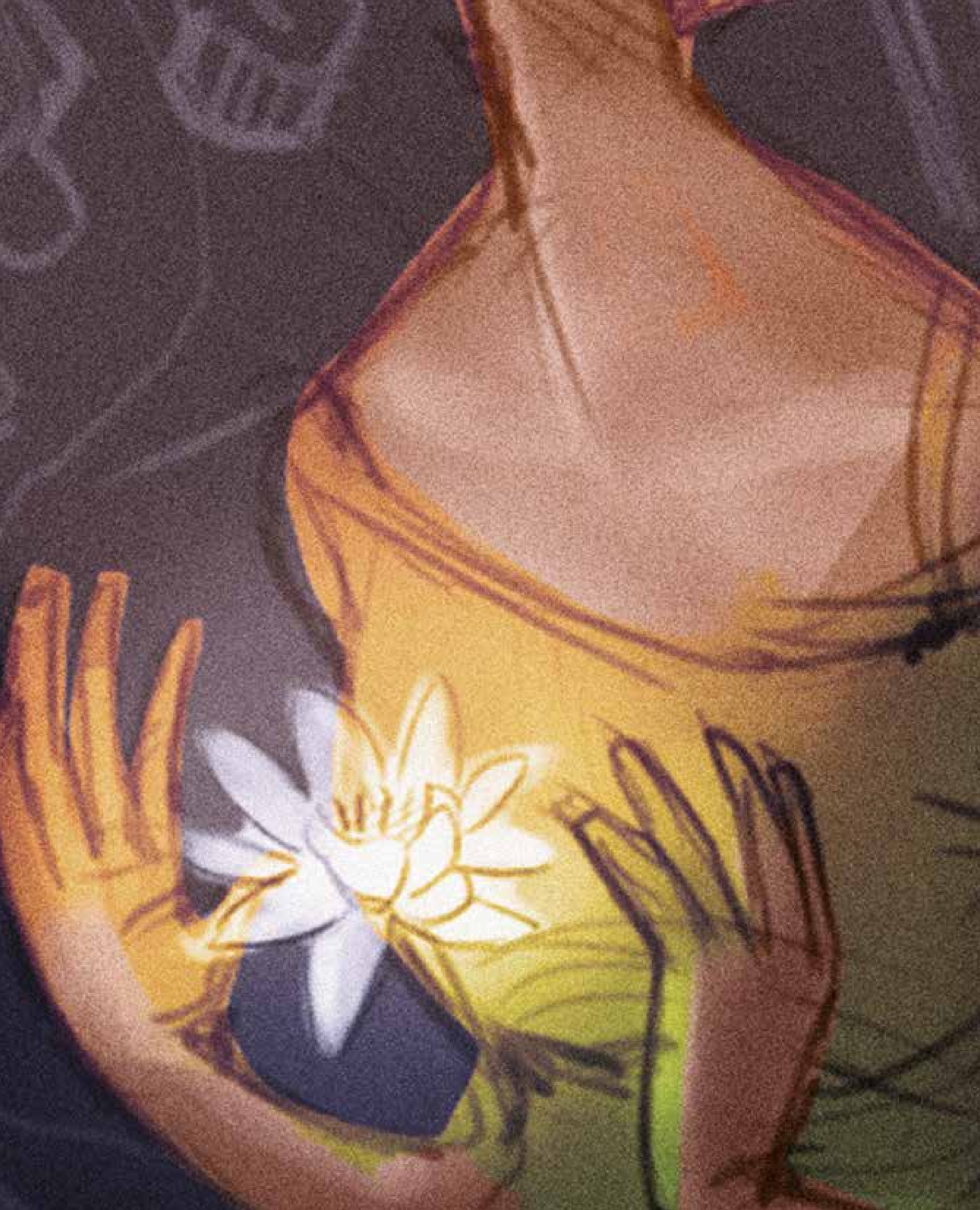
STONES AND FEATHERS

The editorial work was made with the statements of doctors and patients collected on the website *www.ilsensodelleparole.it* between September and November 2020. These contributions were made considering several studies on doctor-patient communication in oncology and on medical linguistics (including those of the research group *Remedia - Lingua Medicina Malattia*). To add value to these statements we also looked at the recent orientations of narrative medicine, based on the interpretation of the subjective experience of an illness, well beyond the simple clinical history; i.e. as attention to the patient's world, his/her universe of meanings, his/her stories.

What has emerged is the need to establish a communicative space in which patients can share their perception of an unknown term - threatening and not infrequently painful - without feeling relegated to their patienthood. Terms that, when spoken or written by the doctor without further explanation, end up burdening the disease experience with a sense of anguish and shame. «Words are like stones and doctors often throw them like feathers», said one of the many people who bravely and generously agreed to open up about their experience as patients, thus making a decisive contribution to the development of this work. This dictionary is dedicated to all of them.

Giuseppe Antonelli and Giacomo Micheletti

Minimum reference bibliography at page 83



INDeX oF WORdS

The aim of this small dictionary is to offer a first map of the words related to care and treatment, considering the different views of the doctor and the patient.

Terms were selected based on a specific bibliography, on the preliminary investigations carried out as part of the project (analysis of the online sentiment, focus groups with doctors and patients) and with precise lexicology and sociolinguistics criteria. The selection of some specific technical terms of the medical language, mainly coming from the therapeutic field and related methods, was aimed at guaranteeing an adequate level of variety and representation. In order to do so, several criteria have been considered: etymology (from Greek to Latin to English); word formation (from acronyms to derivatives); frequency of use outside the medical industry. The dictionary also contains some of what linguists call «collateral technicalities»: words such as **remission**, that do not refer to specific notions of the discipline, but are often used by the specialist to give his/her speech a more technical register. Usually, it is precisely these technical words that tend to create a distance between the doctor and the patient.

A distance that this small dictionary would like to help reduce. This is why, in dealing with each of the words considered, we have always taken into account the doctor-patient relationship and therefore, the way in which each different point of view tends to interpret the words. Technical words spoken by the doctor such as **diagnosis** or **prognosis**, for example, can evoke emotions such as fear and hope in the patient's perception; **relapse** and **remission** can give rise to anguish and thoughts of survival; **PET** the idea of control, and **surgery** the idea of risk. All of this is intended in the context of a common **path** that starts from **prevention** and its relationship with health and arrives at **research** as the keyword for care. To care about words is to care about people.

Each entry in the dictionary starts from the word's etymology to encourage a reflection on its meanings and uses.

The text in red italics come from the statements of doctors and patients who took part in the project.

The words in bold in the text refer to terms to which other entries are dedicated.

PREVeN TIoN

The concept of prevention concerns in the first place the set of behaviors and habits that each of us can introduce in our daily life to reduce the risk of contracting a serious disease. Proper nutrition, a lifestyle without excesses and regular physical activity are the essential ingredients of a life lived in the name of wellbeing.

While it is the responsibility of the medical authorities to make the public aware of the benefits of such a lifestyle, it is up to each individual to adopt behaviors able to limit the so-called risk factors (smoking, alcohol, sedentary lifestyle, etc.). In this sense the individual’s right to health also entails the sharing and active practice of a health culture created day after day based on self-respect.
Another important topic - not limited to the field of oncology - is that of «secondary prevention», where the formulation of an early **diagnosis** through checks and mass screenings can prevent the progression of a certain disease.

> *«I believe that the term "prevention" is not always used correctly. Inviting women to do Pap smears and mammograms is undoubtedly an excellent way to prevent the development of tumors to an advanced stage.*
> *It is however ambiguous to declare that a healthy lifestyle can prevent diseases, including cancer. It is absolutely true that smoking, not exercising or eating junk food is harmful and in the long run may result in becoming ill, but it is not true that if we don't do any of these we will not fall ill. Diseases and treatments must be communicated in a clear way, one falls ill and dies at every age and with every lifestyle. Prevention will make us live better, but it does not protect us from all diseases».*

As an old slogan says, «Prevention is better than cure». But if by cure we mean a **path** of communication and listening with the goal of improving quality of life and wellbeing, then prevention intended as health education becomes an essential step of the **treatment**. Unfortunately - as the statement we have chosen to mention reminds us - «one falls ill and dies at every age and with every lifestyle». Nevertheless, the promotion of the information underpinning the culture of prevention is now one major requirement for many patients. And, as such, it is one of those fundamental patient rights that only recently has been fully recognized by the institutions.

Prevention probably «does not protect us from all diseases» but contributes to the spread of an idea of medicine in which the responsibility of personal daily choices, especially in the context of a dialogue with the doctor, is no less important than medications and **treatments**.

Prevention

DiAgNOSis

The word diagnosis (from the Greek *diágnosis*, literally «to know through») represents the moment of discovery, of the disease identification by the doctor based on the examination of the symptoms manifested by the patient and the tests performed. The process of formulating a diagnosis also includes the anamnesis (*anámnesis*, «memory, reminiscence»), in other words the reconstruction of the patient's clinical history through the collection of information on his/her health condition and the diseases running in the family.

> *«To this word, I associate an experience of pain and loneliness, a feeling of free fall, of darkness and distance from everyone. Anguish».*

> *«The word "diagnosis" reminds me of an axe over my head and so much pain... but also hope. For a rebirth».*

For the specialist, diagnosis indicates - objectively - the communication of a clinical judgment, the result of a delicate interpretation of the patient's overall picture. A firm point on which to work, a first certainty that helps to have a clear picture of the disease. For the patients, however, this term often represents the threshold of a dramatic change of physical, psychological, and emotional nature: the loss of their habits, of the control over their body, of their life plans. The loss of meaning.

The «axe» (also called «sword of Damocles») that recurs in the patients' narration is the clear metaphor of a severe sentence. The one that can suddenly befall in the life of the person being diagnosed with a **tumor**. Giving a name to the disease, especially when the disease is still surrounded by a frightening halo, can induce a sense of anguish in those who find themselves ill.
Feelings of fear, abandonment, helplessness always characterize -

even in case of positive **prognosis** - the experience of cancer patients and their loved ones (the so-called caregivers, who take care of a family member or a friend in difficulty and are too often forgotten to be mentioned in the official story of the disease). The first meetings with the doctor: and then therapies, side effects, waiting for the **surgery**, the fear of a **relapse**... In every moment of the therapeutic **path** there is the risk of sinking into a radical crisis.

As the doctors who are most attentive to the emotional experience and expectations of their patients know, a diagnosis is firstly and in any case «the beginning of a new story from which you can't go back, even if you heal». Integrating the disease into one's life, learning to move forward and accepting oneself again becomes the primary task of a doctor-patient relationship that must be based on transparent communication, but it also must be welcoming and trusting at the same time.

The «rebirth» mentioned by the patient in the second statement, then, is something different from the physical healing from the disease. Something, perhaps, even more precious: the opportunity to give a new meaning to the experiences, the relationships, and the time that life has gifted us.

TUMOR

The word tumor literally means a «swelling» or «lump»; in our case, it designates an abnormal tissue formation caused by uncontrolled cell proliferation. If this formation tends to invade the surrounding tissues, damaging them, it is called a malignant tumor.

> *«It is a word that evocates a terrible fear as soon as it is spoken and until very recently it was equivalent to a death sentence; even now [...] although we know that people do not always die of cancer, for the patient who receives a diagnosis it still has a strong emotional and shocking impact. It is important that the doctor is aware of this and acts with tact and also gets information about the patient's family and if he/she can get some support from someone».*

For the doctor, the tumor is primarily a disease that needs to be treated

with specific procedures. For patients, despite the huge progress made by scientific **research** in recent years, this term, and its synonym cancer (often perceived as more aggressive) continue to evoke the idea of a «bad disease», an «incurable evil» (a «certain death», in short), and therefore it is sometimes considered a taboo by the doctors themselves and therefore avoided.
A patient shared a bitter, tragicomic scene in simple language that highlights lots of misunderstandings, embarrassment, and condemnation that tumor, this disastrous word («you croak, you die»), brings with it.

> *«What is that? Is it Latin? It means a bump?*
> *How ugly is this face to face. This finger pointed at you. You, you: you croak, you die.*
> *Madam, but no, it's not you, don't take it personally, it's a leio: leiomyosarcoma».*

Many are the euphemisms, the «soft» words, words that are hard to understand with which modern medicine tries to reduce the dramatic effect that words related to cancer still have on the patient's mind, such as: the Latin words *exitus* and *obitus*, the adjectives bad or unfavorable (in relation to a **prognosis**); the expression secondary or recurrent lesions (for **metastasis**), the acronyms and abbreviations for many clinical reports (*Ca* or *K* for carcinoma).

Today, however, in line with the promotion of patients' active participation in the diagnostic-therapeutic decisions concerning them (that can be summarized in the so-called «right to an informed consent»), the need to completely rethink the oncology communication vocabulary and its euphemistic strategies is widely claimed.

A cancer **diagnosis** - we have seen it - induces in those receiving it a sense of deep fear and helplessness; sometimes also guilt, as if the illness were a sentence they deserved.

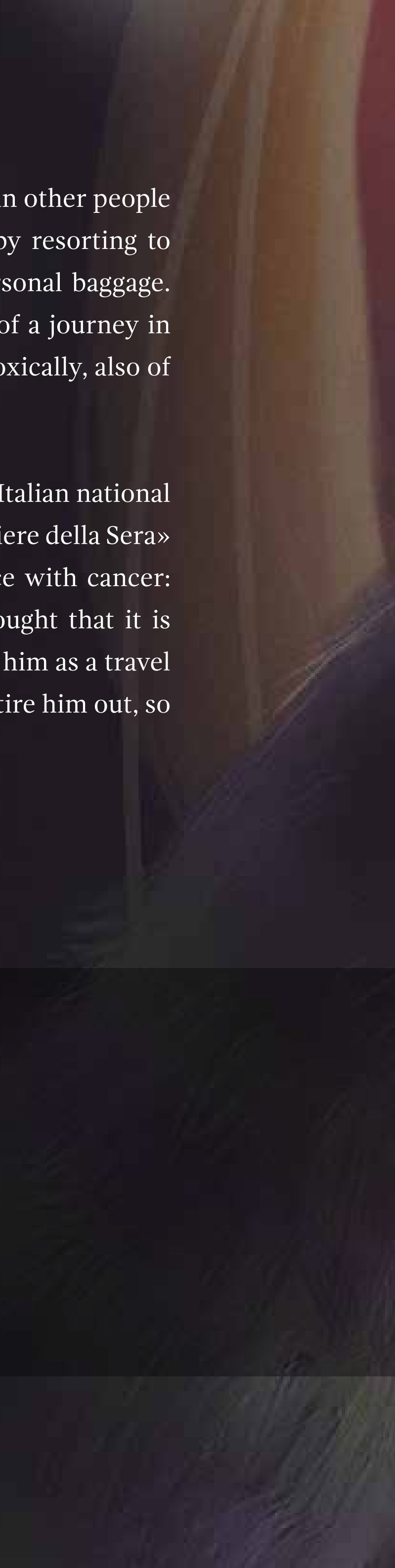
It is therefore necessary to consider the emotional burden of certain words and the controversial images that traditionally accompany them in the medical field. The typical use - when speaking of the disease and, more so, of the therapy - of war-like metaphors (struggle, battle, war) is likely to aggravate the patient's distress.

In fact, according to philosopher Susan Sontag, treating a disease as a war transforms patients in to future dehumanized «designated victims»: the inevitable civilian victims of a conflict that «lose their right to citizenship as healthy people to get a passport as ill people and the burden it entails». This way, in addition to being victims of the disease, patients are also victims of the disease metaphor: getting sick means being hit by the enemy and dying becomes a shameful defeat.

Moreover, besides distorting the relationship between the individual and society (while the right to health is a matter concerning the community as a whole), the use of war metaphors burdens the patient with responsibilities and expectations that can be detrimental for the **treatment path** undertaken, potentially hindering, in case of **chronicity**, the acceptance of a satisfactory quality of life despite the disease. «Victory», in this context, can also mean a long survival after: the possibility of continuing to cultivate relationships and interests and to plan a future that includes the illness. Since future too, as well as cancer, is a word that the patients and their close relations can learn to pronounce without fear.

So, we can talk about cancer and tumor, we can confide in other people without fear of confessing a crime, and we can do it by resorting to new, less distressing images, even tapping into our personal baggage. Images that communicate the sense of a commitment, of a journey in the company of your doctor and your loved ones. Paradoxically, also of the tumor itself.

Gianluca Vialli, former football player, now Head of the Italian national team Delegation, who in an interview (quoted in a «Corriere della Sera» article of October 11, 2020) spoke about his experience with cancer: «I never considered it a battle because I've always thought that it is better to keep cancer as a friend. I've always considered him as a travel companion I could have done without. Now I will try to tire him out, so that eventually he will let me go on».



TumoR

PRoGnOsiS

The Hellenism prognosis (from *prógnosis*, «prediction») indicates an opinion about the evolution or pace (course and outcome) of a given disease. It's an assessment made by the doctor based on the nature of the disease itself as well as a number of factors such as the patient's condition (age, gender, general health, previous illnesses), available therapies, risk of possible complications. Depending on the case's severity, the prognosis may be benign/favorable; confidential (if the situation is susceptible to rapid changes, even serious); or unfavorable/inauspicious, two euphemisms technical used in medical language to mitigate the drastic effect of a negative or rather fatal outcome for the patient.

> *«Favorable or unfavorable. Good or bad. Black or white. What's going to happen? What is the prognosis?».*
>
> *«Not the word itself, but the meaning reassures me.*

> *Whatever the prognosis, I want to know».*
>
> *«We observe the eyes of our doctors who maybe know but are not always in front of patients who are able to live with their body's failures».*
>
> *«We have never asked how much longer we have left to live, but this has always been our fixed idea».*

For a patient who has already received a **tumor diagnosis**, the communication of the prognosis by the doctor appears as a turning point of his/her future («black or white»), or a bet placed at the roulette table. Some people, like the patient in our second story, find the strength within themselves to accept the outcome of the bet: whether the prognosis is favorable or not, it is from there - when the doctor formulates the prediction - that one can begin to discuss the most suitable and safe **treatment**. Other patients see the prognosis as the definitive confirmation of a «breakdown», a malfunction certificate that foresees a future of therapies and clinical check-ups, and therefore they prefer to postpone the moment when they get to know about the disease.
Because it is the future, namely the space of hope, the inner horizon on which the word prognosis casts its shadow of uncertainty: hope to heal, to feel good, to feel better; hope to be able to accept ourselves again and to accept the fact that our body is not an indestructible machine.

The term prognosis, moreover, tends to be confused by many patients with another term, i.e. **diagnosis**. Not only because of the common

Greek root, which gives these two ancient words a somewhat obscure and incomprehensible trait, but also, and above all, because both, whatever the nature and severity of the disease, can resonate in the ear of the patients as a confirmation of their condition: the memory of the moment when the disease officially entered into their lives, disrupting them.

The aid to cope with the proposed **treatment** therefore also depends on the use of the words that are as clear and shared as possible and, if spoken paying real attention to the person's feelings and dignity, can represent the therapy building blocks. For this reason, it is critical that the doctors, when communicating a prognosis (or a **diagnosis**) and beginning the **treatment path** along with the patient, act as the guarantors of a true alliance based on their best communication skills; on the ability to listen even to those silent questions that all patients, despite everything, continue to ask themselves.

Pro Gnosis

PaTh

Today the metaphor of the **treatment** process as a path (or journey) tends to prevail among doctors themselves, as shown by the first two statements. This image is in fact particularly suited to symbolize the shared nature of the **treatment** process, a responsibility that is taken off the sole patient to rest also on the shoulders of health professionals and caregivers. In this way, by using a collaborative representation, medical language naturally takes charge of the cancer patients' expectations: the expectations of people - travelling companions - with whom to share this journey.

> *«We know where we start, we don't know the destination, but we are aware that the road will be challenging. The path is shared to make the baggage less heavy. The baggage is carried not only by the patients, but also by their family, their doctors, and anyone who takes care of them. When I explain the path to the patient,*

> *there's only one really important message I have to convey: that I'll be there. My presence at his side».*
>
> *«A journey with unknown intermediate destinations and a final destination that can be more or less pleasant and more or less desired. [...] We need a toolbox, a bag of resources to take with us. The hope is to not always walk alone, but to meet people when necessary. I also see it as an opportunity to not remain static and inert, but to go ahead, no matter how, balancing energies and goals».*
>
> *«If there is a path to take, it means there is a road, you are not facing a wall».*
>
> *«I have learned to live again, to recreate a normality with this uncomfortable companion, and the path was not easy especially at the beginning. The stairway is long, I hope to take some more steps».*

No two **treatment** paths, as patients remind us, are going to be exactly the same: every journey is made of stairs, steep and unexpected climbs, but also moments of reflection and rest, and course changes. One thing however is certain: wherever it leads, the **treatment** path always involves the idea of a progress, of an open project, of getting closer to a destination: «you are not facing a wall».

In the end every journey is always full of uncertainties, exposed to the risk of taking the wrong way: it always requires the presence of a «toolbox» in case something happens. And by tools we mean the knowledge with which you venture into the unknown, the teachings to treasure day after day.
The image of **treatment** as a path therefore reflects the one of life itself as an itinerary made of always new experiences that allows the patient to even accept the disease, «this uncomfortable companion», in the journey that we are all called to take, one step at a time, in the company of our loved ones.

At the meeting point between the specialists' language and the patients' experience, the journey as a sharing and discovery process then takes on a further meaning. It alludes to the gradual conquest of a new awareness: the one concerning the time that life has accidentally granted us and that only in moments of uncertainty we learn to fully live and appreciate.

Path

SuRgERy

A typical term of modern medicine, as well as in oncology, a crucial moment of the therapeutic process. In the patients' narrative this word is associated sometimes with a sense of «liberation» and other times with feelings of fear, loneliness and pain.

> *«The word "surgery" for me conveys a feeling of coldness, of something sterile and detached. Cold as the knives that will be used. You do not develop a real communication with the surgeon, often you see nothing and if you got anesthesia, you wake up as if from a dream. Only then you feel some sense of humanity, as if you were returning from a dream».*

> *«Waking up alone and feeling an atrocious pain, not even able to utter a word. No one near me!*

> *They call it the recovery room because there is no one here. I try to check the wound with my hand to understand what is missing, I can move my arm, I move it, I grab an I.V. stand and start slamming it against the bed… someone will hear me. They will hear the voice of my pain».*

In these grievous tales, besides the huge suffering there is also room for an equally moving will to heal, for hope in a decisive intervention.

> *«Although I have done many surgeries, I must admit that I do not attribute a negative connotation to this word. Far from it. […] Surgery means being able to act, therefore being able to have an active behavior that could somehow neutralize evil».*

> *«If you can intervene you can repair. There's time to fight. There's time to try. Whatever the evil may be».*

Unfortunately, the patient cannot always undergo surgery: the nature or stage of the disease, the general health conditions sometimes require giving it up; what some people have described as a «lost opportunity».

It is worth remembering, though, that the concept of surgery should not be strictly confined to the specific act. It may in fact refer to several situations ranging from the **diagnosis** communication to the different therapies, and possibly to the many check-ups or *follow-up* visits you have to undergo after a surgery in order to avoid the risk of a **relapse**.

In each of these moments the patient manifests - not necessarily with words - the need for psychological and emotional support. A support concerning the perception of oneself and one's own body; the difficulties in communicating with family, friends, colleagues, and health professionals; the effects of the **treatments**; the desire to continue to cultivate one's passions.

These are all situations in which it is necessary to intervene through a responsive and empathetic dialogue, so that the people in front of us find in themselves motivation and positive energies to recover their inner balance instead of living with the **tumor** as a sort of punishment.

Yes, it is possible to heal from the disease; but, as patients teach us, it is also critical to learn to «neutralize the inner evil» that often comes with physical suffering loaded with fear.


PET
PET
PET
PET

PeT

The acronym of Positron Emission Tomography, PET, indicates an advanced diagnostic technique able to show the localization and the size of a **tumor**; verify the effectiveness of a **treatment**; detect any **remission** of the disease or, in the most serious cases, the presence of **metastasis**.

«For me, PET scans have become "vital"! I have to say that after six months of chemotherapy I was devastated, in both body and spirit. I finished my last infusion on August 8, 2018, and on August 10 my mom, who my sisters and I had taken care of for 16 years, died. After a week, my oncologist told me that I had to get a CT scan before I could get radiation. I did the CT scan, and, after another week, the oncologist asked me if we could meet. I went to her office, and she told me that the CT scan didn't go well.

> *It showed traces that seemed to be like lung metastasis and in the right breast (the one operated) another mass was visible, another tumor. I had no reaction. I was so shattered after everything I had experienced that I was not even aware of what I was being told. I just thought, without telling anybody: "This means that I will join my mother, who has just got back to the Lord's house!". No, I wasn't scared at all. I was so disheartened that nothing could scare me anymore. After 3-4 days from hearing the terrible news, the oncologist called me again to tell me that, after consulting with the head of radiation therapy, I had to get a PET scan. I did my PET on August 31, 2018, and after 2 days the oncologist happily told me that the PET was fine. Soon I would be able to start my radiation therapy! Thank God!».*

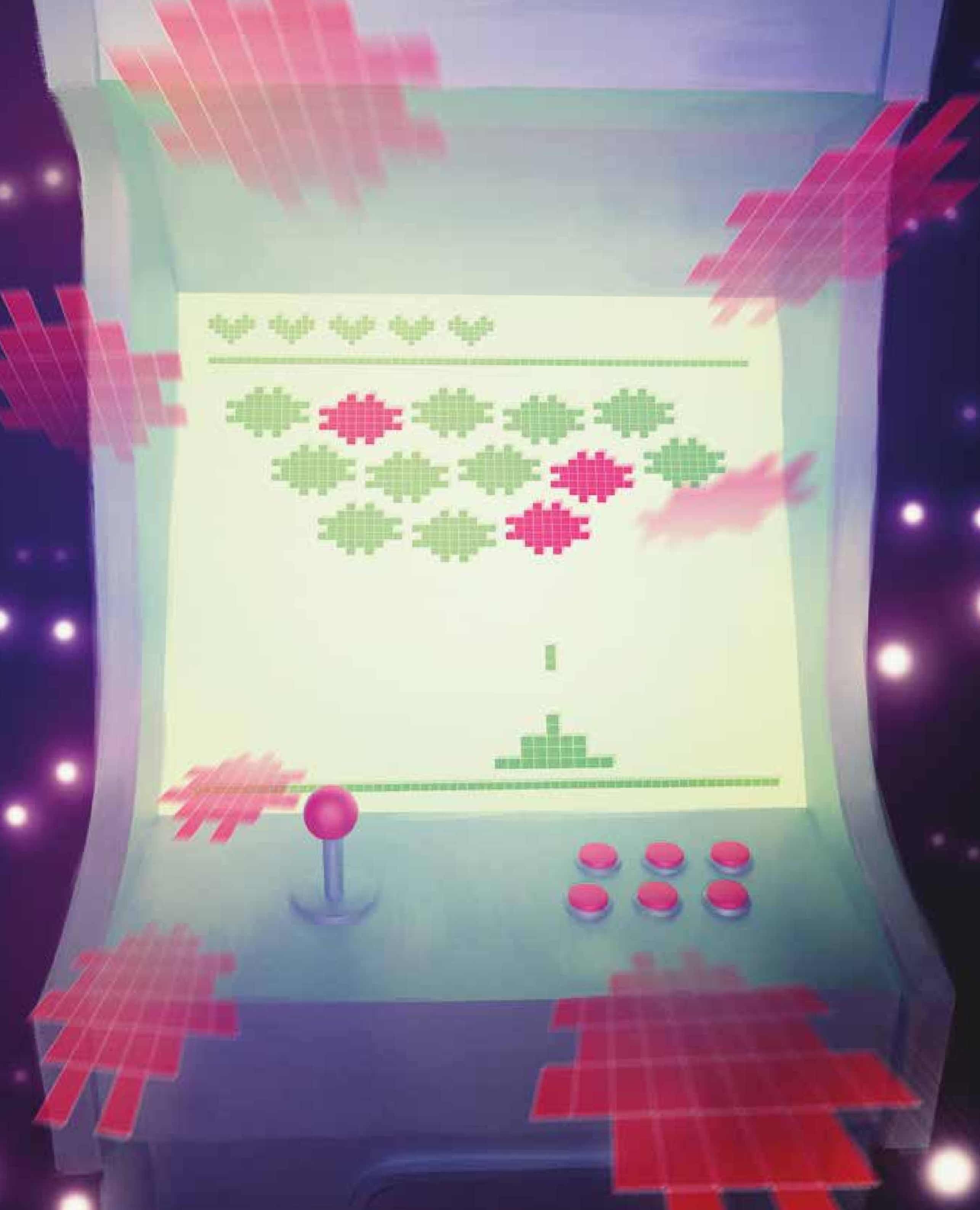
Although, as our consultations reveal, the meaning of the acronym PET is usually unknown to many patients (like CT «Computerized Tomography»), there is no doubt that often it represents - as we saw in the statement - a clarifying moment within the therapeutic **path** that can foster a new confidence in the **treatment**.
The moment of confrontation with the truth that regular examinations or visits represent, though, can also be a source of fear for the patient (or the caregiver), once again tossed in a solitary battle against the disease.

> *«I lost my dad who was only 45 years old, and my mom is fighting her second breast cancer. We try to fight and live while waiting for the next check-up. Some days it is very hard».*

The concept of control, in the patient's emotional perspective, can also refer to the sense of loss following a disease **diagnosis**: to the feeling of losing control over your body and your future. It is worth mentioning that today the most attentive standings to the development of the so-called patient empowerment tend to promote the right to have full information in the field of medical communication. As Rosaria Bufalino and Antonio Florita write:

«The demand to receive accurate and full information on one's state of health, on the possible therapies, and on the human, technological, welfare and legal resources available is, in summary, the first and foremost expression of the need to maintain the perception of internal control over one's own life events and, therefore, to plan decisions and make choices at the maximum level of autonomy and awareness. Ultimately, to be the master of one's own destiny».

Control: but also, independence, awareness, choice, planning. These are the key words for overcoming a bad doctor-patient relationship pattern characterized, until a few decades ago, by «a sort of communication based on a secret understanding in which the doctor did not say, and the patient did not ask» (according to Franca Orletti and Rossella Iovino). The planning of an effective **treatment path** starts precisely from this desire to «be the master of one's own destiny». The desire for oneself that, precisely because of the suffering and the fear, one must be helped to find again a unique trace of destiny and follow it bravely.



MeTASTaSis

Metastasis (from the Greek *metástasis* «mutation, displacement») means the migration and remote reproduction of malignant cancer cells, especially through the lymphatic or blood system. Although, compared to not so many years ago, the new therapies available offer the patient completely new **treatment** (and life) prospects, in the case of a metastatic disease the **prognosis** remains a highly sensitive matter.

> *«Fear, anguish, a sense of death and an unconditional surrender to life and to the ability to fight. The idea of having metastasis and having to fight and suffer again makes me only want to put myself in a corner waiting for death, without doing anything else».*

> *«"Metastasis" is one of those terribly scary words, it means that your disease is progressing. I think that after enduring treatments such as chemotherapy,*

> *radiation, and hormone therapy, this is the part that I fear most [...]. Medicine is certainly making progress, but in addition to helping the body of cancer patients it is necessary to act also on the psychological aspect because in the end you can "heal" but you will never let go of the fear, even if you try to face life with a positive attitude».*
>
> *«Living this reality is extremely hard, but it is also true that every moment of satisfaction and peace, even the smallest and shortest (and fortunately, we all have them), turns out to be a bubble of happiness. The key word is resilience».*
>
> *«Metastasis means certain death. You don't just think about what's in the middle. But this "middle" is fundamental. Finding the key to exploring this middle territory is the real challenge for new medicine. A medicine that should include, as an integral part, drugs, words, gestures, narratives, and attention to the sick person, not to the disease».*

On the one hand, the «corner» in which the patient hides, far from life, invaded by a terrifying sense of death. On the other, the vast therapeutic horizon that medicine must learn to fill also with «words, gestures, narratives and attention». Because without a genuine emotional and psychological support, any recovery is bound to remain incomplete. According to patients, a **diagnosis** of metastasis is an extremely difficult moment within the treament **path**: debilitating therapies, the need to continuously monitor the situation with a different **prognosis** according to the organ involved, the awareness of the disease's inoperable nature, the giving up of hope for a complete **remission**. Even doctors themselves sometimes struggle to address this word, as a doctor's comment reveals:

> *«The ugliest word in oncology, a word that is not normally used with patients (synonyms are preferred: migrated cells, repetitive or secondary localization, even secondary masses!) unless the patient pronounces it himself. It is used among colleagues and with the relatives. It evokes inevitability and death».*

Avoiding mentioning the disease - resorting to more harmless (because incomprehensible!) technicalities and leaving to the patient the responsibility to translate them into a «death» sentence (as we read in a statement) - is hardly the best way to help people overcome their fears.

But today as new **treatments** offer prospects of, at least, **chronicity** and therefore of a decent long-term survival to an increasing number of patients with metastasis, an ethical duty is required to overcome the sense of «inevitability» that - in the doctors' vocabulary - still gets associated with the names of the disease. «Inevitable» literally means that «it cannot be tackled», while we know that it is not so, not anymore. Today the **tumor** - even in its metastatic forms - is a curable disease and it is necessary to learn to speak about it without embarrassment. Even if it is not possible to operate or remove all types of cancers, this does not necessarily mean that we must remove those words with which the patient learns to live daily in his intimate process of self-acceptance as a part of his **treatment path**.

TreAMeNT

Treatment, a key term of the **therapeutic** process, includes all the therapies, drugs and, in general, the procedures adopted to treat a certain disease.

«For me, treatment is beyond dispute. You simply have to do it, in all its forms, whether direct or secondary, no matter how inevitably exhausting it may be. At first the prospect, though well explained, it is depressing. Maybe you try to complain with the doctors, because you do not want to wear the bandage for two months after the mastectomy (to say the easiest thing). But then you travel across your treatment path, one step at a time. [...] Obviously there are many types of treatment, and every situation is different, but in the face of something so disruptive, uncontrollable and out

> *of my "habits" (even my health habits), I have chosen to trust and rely on doctors, who know this field better. Better than me, at least. I never had a*
>
> *doubt about the treatment (which I often strictly associate with the famous "protocol"), but rather about my reactions to it».*

The metaphor of the treatment as a «**path**» to travel «one step at a time» is a recurring theme in patients' stories: the initial discomfort for the proposed therapies, the fatigue and the suffering caused by certain side-effects; but also trust in the doctors, the discovery of an unexpected strength and endurance (on the part of the patients, of course, but also of the family members who support and accompany them on this journey).

Treatment is a word that expresses the totality of the crisis generated by cancer: because of its repercussions beyond the mere physical sphere and of the involvement of all the «actors» present in the scene. Including the doctors, of course, who increasingly refuse to have a paternalistic and outmoded vision of the treatment according to which «the patient "accepts" and the doctor "acts"». On the contrary - a doctor told us - it is increasingly more important «that the patient is active, involved and competent».

A nurse who enthusiastically welcomed the invitation to take part in our consultation points out that: «Treatment should not be intended exclusively as a diagnostic-therapeutic process; however, it should include all the "cares/cures" and attention for a cancer patient, and also something more». The wish to feel accepted and have their interpersonal needs recognized may explain the distrust of many towards a word that - as the synonym therapy (from the Greek *therapeìa* «remedy, healing») or the famous protocols (with their bureaucratic flavor) - can convey something that is sort of foreign and impersonal.

> *«I would utilize the word "treatment" for objects only. For people, I would use words like "care" or "attention"».*
>
> *«Carpets, blankets and car bodies are TREATED to preserve them, to protect them from the weather and the seasonal changes. Carpets, blankets, and car bodies, they don't think, don't move, don't talk, don't listen. TREATED patients must be... patient: prepared to wait and to be deposited here and there».*
>
> *«It is a cold and impersonal word, just as some healthcare professionals are. I really like the word "care", which has a much deeper and broader meaning».*

Broader and more inclusive, the meaning of the word care goes beyond the treatment of the patients - intended as the carriers of an organic disease - and implies the establishment of a relationship that's able to involve them - starting from valuing their experience - and help them to take care of themselves through thoughtful behavior. If treatment, by definition, is provided, care is the creation of a relationship between two (or more) people: the establishment of a new world in which words and emotions, expressed and shared, start to make sense again.

tReaTmEnt

ReMisSiON

Remission comes from the Latin word *remìttere* «cease, decrease» and indicates the attenuation - possibly the progressive disappearance - of one or more characteristic symptoms of a morbid state. In oncology, this phenomenon is also indicated by the term regression.

«I don't have a precise memory of when I first heard the word "partial remission", but I perfectly remember when one of the doctors following me announced the complete remission. He scrolled meticulously through the PET images, and I remember crying, with my parents besides me, while he described them».

«To the word "remission" I associate liberation, freedom, return to normality».

> *«A doctor told me that if the therapies worked, I would go into remission, but also that remission does not mean complete healing. One can speak of complete healing only after six years... Now that I am in remission, I still feel sick and every check-up is still very stressful because I don't know how likely a relapse is, and although I got my "previous" life back, I continue to feel uncertain about my survival».*

The **treatment** is working, the doctor shows its beneficial effects, and then, in the patients' stories, the good news of a **tumor** remission is understandably associated with the idea of survival: the feeling of being born again, with the «liberation» from the fear and the sufferings of the **treatment**, with the dream of having finally left the disease behind. But that «previous» life that remission seems to promise is often destined, as the patient of the third statement demonstrates, to stay in quotation marks. At least for a while, even in case of complete or total remission. The news of disease regression in fact - although very positive, to be welcomed as a confirmation of the efficacy of the therapy used - is never an immediate synonym with recovery or complete healing. It is necessary to undergo further **treatments** over time, to avoid or promptly diagnose a possible **relapse**. This is also why, for some patients, the term remission is a source of anxiety and concern: «because I don't find it a reassuring word, as if in the end it were necessary to maintain a slight but permanent alert state».

Some other people interpret this word in the light of their Catholic education («remission of sins») and the sense of guilt that the negative culture around **tumor** still carries with it; as if, to the patients' ears, the news of remission were equivalent to the forgiveness of their faults as sick people.

Once again, then, we understand the importance of a communication that is as truthful, objective and, at the same time, as cautious as possible. Especially where the hope for a quick or imminent recovery could deceive the patient and take away the energies necessary to continue on the **treatment path** they had agreed upon.

A long journey, sometimes longer than one would like, that may eventually come to an end, and - as recent statistics confirm - more and more often ends with the happiest of news.

Remission

ReLapSe

In medicine, relapse means the reappearance of the symptoms associated with a disease that is on the road to recovery or apparently cured.

«The tumor has started to grow again or has returned. It is what we have been fearing for months».

«And then, when this other word comes, “relapse”, everything becomes clear in your head: it is a confirmation of the tragic situation you are living, an anxiousness of imminent death. Also, it is the confirmation that you were right not to believe in the recovery and that the doctor who suggested it was wrong. So, you wonder if, when talking to you, the doctor sugarcoated the situation and deep down you think that he lied because he cannot not know that healing is more of a myth than a reality.

And having believed it a little bit, when your brain was swinging between living or dying, it now sounds ironically stupid and the anguish of death at this point is unstoppable. So, for me, it's not the word "relapse" that weakens the communication between me and the oncologist, but rather the tragic "healing-relapse" sequence that makes you realize you can no longer believe in everything that the doctor tells you. The word relapse sounds like a "scam". And so, I say, why not consider that the patients do not need sweeteners but truths that can help them cope with such an event. And, I say, it is the doctors' responsibility to come to terms with that, to tell themselves that cancer patients are most often serious patients and aware of their conditions, to accept to do a job where they will also see striking defeats... In short, the doctor must train himself to better prepare his patient, and when the patient properly recovers and heals completely it will bring a huge joy to both».

«Relapse. Every time, a blow to your heart. And even so, the hope you can still do it. Dear doctor, sometimes I felt embarrassed for you, as you could have said it with other words when you were looking into our eyes».

It is not difficult to perceive in the words used by some patients when re-experiencing probably the most difficult moment of their **path** the disheartening anguish caused by a news that - from their point of view – equals to therapy failure. A sort of frustrating return to the starting point that can have a negative impact on the relationship with the doctor: on his authority, on his ability to understand, on his reliability.
In several of the statements collected, relapse is associated with a «lack of confidence in clinical protocols». It induces a «loss of the will to fight» in the patient, who is tired and feels trapped in the image of a solitary war against the disease, up to the point of wondering: «what is the sense of fighting when you know it is a lost battle?». And again: «We will not be able to defeat it», the **tumor**, «we can only slow down a new assault knowing for certain that, should we succeed in driving it back, it will return again and again, each time leaving our body more and more devastated and our soul even more sore… until the final assault».

Reading these stories that tragically express the sense of helplessness felt by many people facing the return of the disease, we can once again understand how the concept of **treatment**, a recurring term in these pages, cannot be limited to the provision of a clinical **treatment**.
A **treatment** process also requires training in patient listening and in the appropriate communication of **diagnosis**, **prognosis** and any news concerning the therapy. It requires not «sugarcoating the pill», not optimistically lightening up a situation that, in case of negative developments, can radically destroy the patient's hopes and the trust he/she puts in the doctor, which are the pillars of strength of the therapeutic alliance. But it neither means simply transmitting the data with scientific detachment and an impersonal manner, as the end of

the last statement highlights: “Dear doctor, sometimes I felt embarrassed for you, as you could have said it with other words when you were looking into our eyes».

Relapse, «scam»: an example of the emotional investment that some medical terms entail for the patients and that they associate with a very subjective meaning. «Scam» is linked to words such as «deception», «fraud», «betrayal»: it speaks of a disillusioned hope, of a suffering left to itself. A failure, a warning not to be forgotten.

ReLaPse

ChRoniCitY

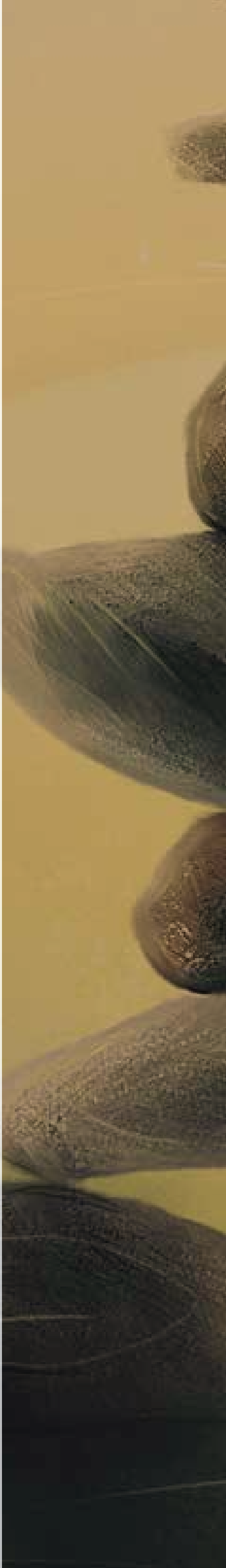
In medicine, chronicity (derived from the adjective chronic, that comes from the Greek *khrónos* «time») indicates the process through which a disease progresses from an acute to a chronic, permanent state. This phenomenon implies the exclusion of a complete healing and the adoption of **treatments** necessary to prevent the return of the disease in the acute form.

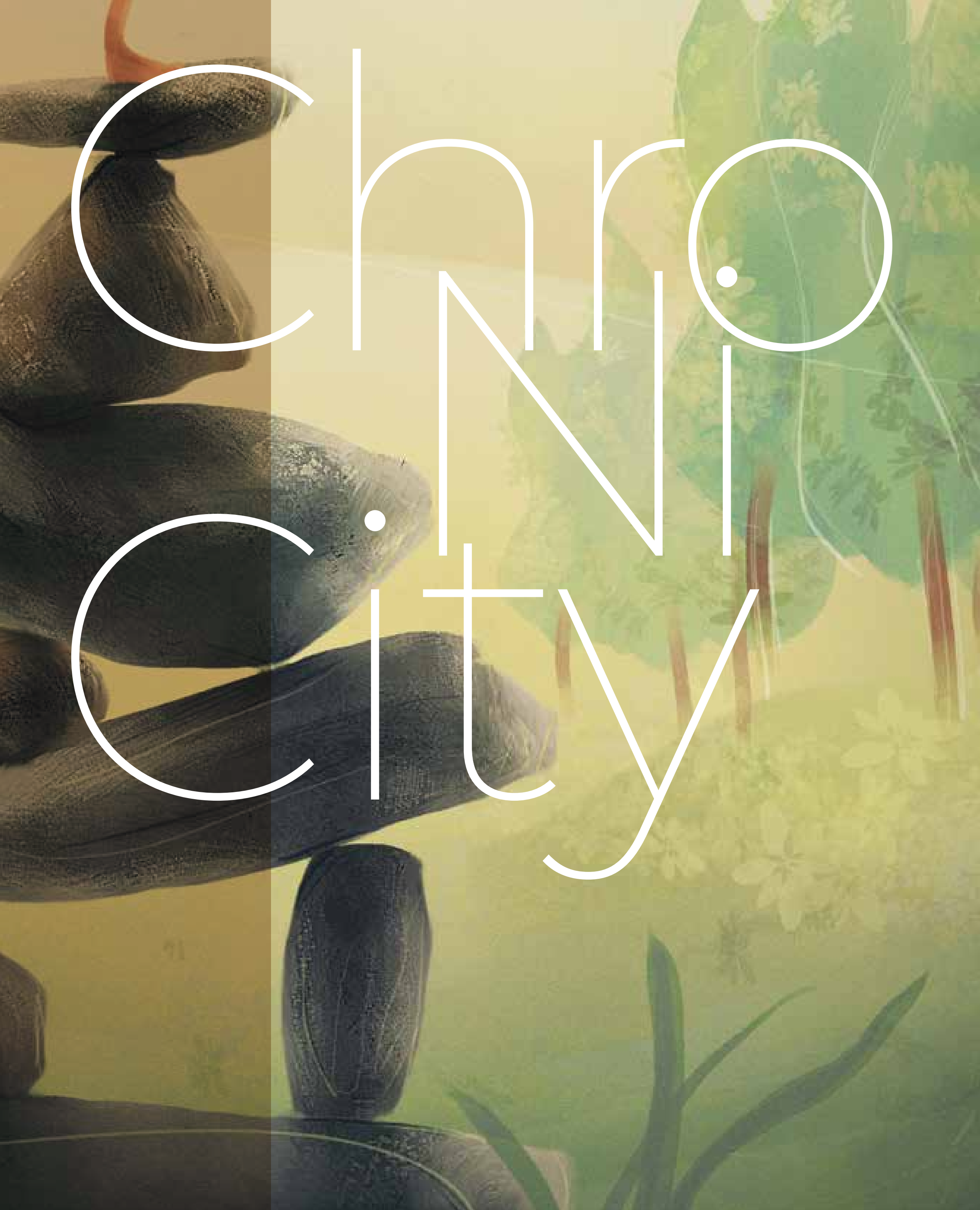
> *«Anxiety. Disability. Hope».*
>
> *«"Chronicity" is a nice word [...] for those who cope with a really serious tumor».*

In the patients who took part in our consultation, the word chronicity generated mixed reactions and feelings: especially anxiety, stress, surrender, a sense of deep discomfort because they have to rely on hospital check-ups and therapies. And it is not surprising that someone also speaks of «chronic discomfort», or the fear of a forced coexistence with this feeling.

For many patients however the chronical stage of an oncological disease (especially when **metastatic**) where a full recovery is unfortunately not possible represents today a valid prospect of long-term survival, an impossible opportunity until a few years ago. Within a **treatment path** that still requires continuous or regular **treatments** (depending on the patient's response), this prospect creates a chance to learn how to control the **tumor** and plan a new life, based on a satisfactory quality of life, full of interests and motivation. A new psychophysical balance that can include the disease within life. Time, which is at the root of the word chronicity and of its meaning, regains its priceless and often unexpected value in the experience of every patient. Time for self-acceptance and time for care, in terms of a human relationship based on continuous support and encouragement.

Care and **treatment** chronicity, then: this could be another possible use of our word, that we suggest doctors to consider. Not limiting themselves to only oblige the patient's questions and requests and follow them but supporting and foreseeing them. Even anticipating - if possible - the reactions of exhaustion and discouragement that all of us have experienced at least once in the sometimes straight sometimes twisty journey that is the time of existence.





Chro
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ReSeArCh

In the scientific field, research includes the set of experiments, investigations and studies carried out within a specific discipline, characterized by shared criteria of methodological precision and reliability. Their aim is to submit to the scientific community new hypothesis, theories, and discoveries to contribute to the general progress of knowledge.

> *«Hope. To believe in the discovery of new drugs. A feeling of gratitude for those who dedicate their lives to research, a work often not recognized and poorly paid in our country».*

> *«Hope, the chance to overcome the disease. The desire that research may help me to heal, giving me the opportunity to live and be less afraid of relapses and metastasis».*

> *«Knowing that a group of young people is searching for a cure to relieve my suffering gives me the energy and the courage to fight with all my strength».*

From the emotional point of view of the cancer patient, the word research (often associated with the metaphor of the **path**, of the journey as the «search of oneself») is synonymous with the hope for a cure. As such, it is spoken with a sense of deep gratitude for the drugs and therapies that are able to ensure healing (or a survival chance) that was unthinkable not long ago.

The results and the possibilities that scientific and technological research can create obviously can have a positive impact on patients' expectations. However, because of the extensive information now available on the new frontiers of medicine, particularly in oncology, a careful balancing act is needed by doctors and Patients' Associations, even more when dealing with news that is not reliable or carelessly emphasized by the media.
The patient's hope is in fact one of the main emotions on which the information dedicated to cancer research plays on: the hope for new drugs, and even more for a definitive **treatment/cure**. With the risk - as it is widely demonstrated - of emphasizing the positive data on healing and survival while cutting back those about the impact of side-effects and mortality and thus contributing to the creation of unrealistic expectations.

The entity of the doctor is called upon to accompany the patient not only through the struggle, but also towards the hopes that lighten up and lead the **treatment path**. He must also be able to listen to questions on the latest findings and the promises of medicine while giving correct information on research results, without ever forgetting, in the delicate weave of emotions that constitutes **treatment**, the meaning of words. The specific weight that certain technical terms mysteriously acquire in the soul of patients and caregivers, the different and unexpected meaning that fear or hope can give to medical words. Ultimately, the necessity of doing research which is also aimed at finding a finally shared vocabulary.

ReSeArch

biBliogRapHy

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