



Letter to the doctors of tomorrow

Fear is
contagious,
but so
is hope

Ada Burrone



Thanks to Roche Italia S.p.A.
for the contribute to the publication

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“As an oncologist and medical doctor I say, ‘Never take hope away!’ I’ve always thought about what terrible pain must be for those condemned to capital punishment to know in advance when their life is going to end, and I believe that a doctor should never turn a prognosis into a sentence without trial.

And it’s not about a pitiful deceit: stating exactly an accurate prognosis in each and every patient is very difficult and often impossible. Therefore, even if it’s just about scientific reasons, a doctor needs to learn to inform his patients about the seriousness of their illness without taking hope away”.

Prof. Alessandro Massimo Gianni

Director, Faculty of Medical Oncology Milan Università degli Studi and Fondazione Istituto Nazionale Tumori di Milano (Milan Cancer National Foundation)

Writing this book was originally suggested to me by a doctor, one of the many doctors I have got to know very well through my work with them on behalf of people affected by cancer.

These doctors seemed to have something in common: the need to achieve a certain level of preparation that would protect them from the risk of emotional overload, or even burnout, caused by an intense job that leaves little space for themselves, and by the enormous burden of pain that is often present in a care relationship.

This made me reflect on the need for specific training in this area, starting at the university stage.

For this reason, I decided to turn to you, the doctors of tomorrow, with the simple aim of showing you a mirror that would give you food for reflection.

Besides cancer itself, I have also lived through difficult, and sometimes life-threatening, physical experiences, and these have brought me into direct contact with good doctors and specialists.

From them I have learned that your job is one of extreme delicacy.

I have seen this in the eyes of those specialists who, unable to deal with the problems of others, retreated behind their role.

And when the role exceeds the person, the inability to communicate becomes inevitable.

There is much talk of empathy, of the humanisation of medicine and of the doctor-patient relationship... But we do not talk enough about how we live and die – two things we all have in common.

Today death is a taboo, just as cancer itself once was. Taboos create fear and the more we try to avoid and escape them, the more they chase and torment us.

Perhaps we would feel stronger and freer if we could somehow include death as a trusted companion within the baggage of our life. Even though you are too young to have death in your minds and thoughts, you will have to encounter it in your profession, and that is why you need to be able to consider it as a reality, and one that you will not always manage to combat or prevent.

But death is not just a fact in and of itself: it is the living experience of a person who will ask something of you, and what they will ask is not only healing.

I firmly believe that the acceptance of our finiteness may help us face up to ourselves and empathise with those who suffer.

And for doctors, whose responsibility is to care before it is to cure, it might perhaps be a good antidote against a certain kind of impotence.

I have seen that those who manage to exorcise the fear of death live better in life.

And I maintain that to live better is also to live longer.

Although I realise I have nothing to add to your knowledge, I want to tell you about some of the things I have experienced as a patient, as the daughter of a patient and as a “co-traveller” of the tens of thousands of women and men I have met through my daily work and who have asked us for help on their journey with the disease.

Let me begin by talking about myself as a patient.

It was 1970 and I did not know I would still be alive more than forty years after my personal experience of breast cancer.

My life changed when, for the first time and purely by chance, I had my medical file in my hands.

It happened while the Medical Director of the Tumour Institute of Milan and I were examining the files of patients to invite to the press launch where we would announce the inauguration of Attivecomeprima.

Our association, the first of its kind in Italy, was founded with the goal of improving the lives of women affected by breast cancer.

Over the years we have extended our activity to all people affected by cancer and their families.

I was 36 years old; I had a child of 12 and a husband who was worried and frightened.

I understood, from the behaviour of those around me, that I only had a short time to live.

I had great difficulty not simply “abdicating” and letting myself go. In fact, it would have been simpler for me to resign myself, start crying and wait to die.

It was a first-class oncologist, whom I shall never forget, who reawakened me to life.

Unlike the others who only looked at the diagnosis, and the consequent ominous prognosis, he smiled, took my hand and, looking me in the eye, reassured me both verbally and emotively, saying, “You’ll make it! I know people who have made it, even in your physical condition”.

I clearly remember how, on leaving his room, I became acutely aware of the blue of the sky that I had not looked at for a long time.

From that day I took charge of my life, accompanied by two faithful co-travellers: the conscious acceptance that I could die soon and the hope of adding more and more time to life and of appreciating it more both in joy and in pain.

I have often thought about that experience with my doctor which opened the door of hope, and it always strikes me that it did not take much time or many words: he simply transmitted to me the hope he had.

Where hope is concerned, Dr Jerome Groopman says in his book "Anatomy of Hope", "the words and actions of those who treat and take care of patients have an influence on synaptic connections", "...true hope, which is made up of a cognitive part and an affective part, can mitigate fear and help us stay balanced and recognise dangers in order to confront or avoid them".

Groopman explains how to learn to distinguish between true and false hope, and understand the difference between optimism – that is, the propensity to think that one way or another everything will be all right – and hope, which is a positive and conscious attitude towards a difficult situation.

Jerome Groopman is a doctor, a teacher at Harvard Medical School and a member of the National Academy of Sciences. He works mainly in haematology and oncology.

In the conclusion to his book he writes, "in fact, I am convinced that hope is as necessary to our life as the air we breathe".

And again, "I follow with great interest experiments on emotion and on the way in which the brain and the rest of the body speak biologically with each other".

Now let me tell you about my father, who had an abdominal cancer that spread to his liver and died at the age of eighty, two years after he was discharged from hospital and brought home to die.

These were the words of the doctor who retreated behind his role, "he only has a few days...".

But another doctor from the same hospital greeted me with the words, "this morning I met a patient of mine that I discharged a year ago in the same physical condition as your father today...".

The first doctor had given me a prognosis, while the second had described a positive fact.

At home my Dad lived well for two more years with the help of a third doctor who managed to give him peace and hope, as well as medical care.

Finally I would like to speak of my day-to-day working experience at Attivecomeprima.

One of my tasks is to welcome and listen to patients and relatives, and to explain and share our activities of human, physical and psychological support so that everyone can choose whether and what to make use of.

By speaking the same language as the people who are living with the disease, we can open up with them a path to spontaneity, which allows their inner burdens to come out and find free expression.

Many people said: "I am afraid of fear". Fear of the unknown of the future. It is a fear of suffering more than of death.

People whose doctor listens to them, makes them feel befriended in a human sense and allows them to express what they really feel, will speak of that doctor with light in their eyes and huge energy in their expression.

But those who have no human reference point and only see a specialist who treats their disease have an empty, distant and wandering look.

In life we all need good and stable points of reference, and when illness strikes this need becomes greater.

We look for people who will let us express ourselves freely and authentically, and who will accept our fears and anxieties, sharing them without diminishing or magnifying them.

The sharing of the problem, unlike its denial, helps us to diffuse it.

Above all we need someone to help us get by in the present, someone we feel is with us in the good times and, if necessary, in the bad.

When I meet patients and their relatives, I usually allow them, or invite them, to speak about what matters most to them.

From my side, I realise that words are not particularly useful; listening is a cure in itself, and to listen we need an open heart and the willingness to accept what the other person is expressing. This is also of great help when we have little time available.

We often end up talking about death, about how each of us imagines it and about those who are pained by the thought of leaving, especially if they have small children.

I am always struck by the fact that everyone feels lighter after facing the demons they have inside.

On this point you will find an appendix with the “voices” of some of the women from our psychological support groups who have looked fear in the face.

I constantly see confirmation of the fact that people who are fulfilled in their own existence have less fear of dying, while those who are unfulfilled put up resistance to the idea and remain entrapped by the fear that is held hostage in their minds.

Now I shall leave you, dear doctors of tomorrow, and thank you for the time and attention you have given this work.

I hope you will all be able to listen to the “patient” inside you and cultivate hope, so that you can pass it on to others in life and in your profession.

Ada Burdette

The voice of those who have found the strength to live and to look fear in the face

"...I dreamed that death was grabbing me by the arm with an incredible force. I didn't want to go with him but I felt that if I resisted with force he would win. So I started speaking to him to convince him I didn't want to die and didn't want to go with him even for a minute. I woke up with the sensation that at a certain point it was he who had left me..."

(Anna - Milano)

"...the main challenge for me was to find the courage to look the fear of dying in the face and I knew that without taking that step I wouldn't have been able to do anything for myself"

(Annamaria - Padova)

"...for the first time in my illness I was able to speak about myself and about my life, and above all I could look the disease and death in the face. If you try and tell someone close to you that you are afraid of dying because you have had cancer, they all too easily run away, troubled by their own fear of death. But in the group it was not like that. The ghosts related to the idea of death and disease were faced, but in company with others who took our hand with serenity, solidity, hope and trust that we were not alone. I found a listening ear, solidarity and never pity; I met women whose physical situation was very serious and learned a great deal from them. I discovered how the thought of the disease and of death can be replaced by serenity and the desire to live intensely and be ourselves throughout and independently of our physical condition. The improvement in our relationship with ourselves and others was one of the central themes of the group

and made it easier to express the anguish of disease and death. For me it represented a foundation of growth that was not only personal but also professional".
(Raffaella - Torino)

"...in any case facing up to my fears, including those about the disease, also changed the way I relate to those I care for. It was a change for the better, in the sense that through this experience and the awareness that we are all mortal I understood that the most important thing is to fill our daily life with positive values".
(Maria Grazia - Monza)

"...as though I were so afraid of dying that I deluded myself that I could fight it by denying it... I learned a way to accept the illness, like living with the idea of death, looking inside myself while still living my life. Now I listen to my needs and not to the fear of a disease to be fought: I understood that you don't fight cancer, you listen to it".
(Enrica - Bergamo)

"...my life was dominated by fear: fear of getting ill again, fear of dying, fear of living. It was as if I always had a shadow next to me that stopped me thinking of anything else. Here I have found understanding and hope. For me it was crucial to bring out my emotions... I felt that to deny it and pretend nothing had happened was not possible. Everything comes out when you least expect it, and catches you with an intensity that's hard to control, and the result is deep anguish. Facing all your emotions and fears with a group of people who speak the same language and have gone through the same experience made me feel lighter... little by little I was freed from the fear that up till then I had seen as omnipotent because I couldn't manage it or channel it. Speaking and facing it with the group gave me the power to control it not by driving it out but by denying it the power it had before. Now I tell myself it is normal for the fear to be there, in fact it would be strange otherwise! I know that what will happen is not within my control, I know I could get ill again and

even die, but that "brighter" side that I see now makes me say I could still live a long time, with the same degree of likelihood. I give the fear permission to enter, but no longer the permission to dominate me. It was very important that in the group we did not just talk about cancer, because this experience forces you in some way to look inside yourself. And so, as well as the desire to give voice to parts of you that, for a thousand reasons, you had buried, you also see emerging things in your life that are not right and that, in the light of events, you can no longer ignore. The cancer gives you a "licence" to live, and says to you - look, you could have died; what are you going to do? Almost as if it were saying you don't have time to waste chasing things that will never change, but you can get them organised and live differently, and thus, perhaps, also live longer".

(Fiammetta - Savona)

"...long afternoons and endless evenings in front of the TV, without hearing a word, unable to watch a film or to read because of a lengthy bout of conjunctivitis caused by my medicines, moments when I realised I was alone, despite the closeness of relatives and friends. Alone because no one spoke my language. Alone because luckily no one else had experienced the disease I was facing. And it was in that period that I felt the seed of a desire to share with other women the experience, the suffering, the discomfort, a common language, and the joy of certain results. I asked for a day off on a Tuesday and got on the train: a three hour journey and a sandwich for lunch. From the Central Station in Milan I got to Via Livigno, and after an hour and a half filled with work, emotions, confidences, smiles and tears, I was happy when I left that welcoming room, a flower always on the table, and rushed back to avoid missing my train home and make the dinner. Sixteen meetings, sixteen journeys to learn how to live better".

(Nadia - Aosta)

"...I wanted to find a place to cry, but not to cry to myself! ... after my first meeting with you I felt that it was well organised and very discreet, and I began to open up in trust. Right away I saw the benefit that

comes from speaking in a group about very difficult things like death, the wish not to die that we had in common and the will to fight; but above all I felt there was a path, and that it wasn't just talking for its own sake, but there was a reason why we could see a road ahead of us and not a dead end. It was like the guarantee of a new life – you don't know how long it will last, but it is new all the same. You were a great help to me, even though you were not always "good fairies". I felt strongly drawn to this thing, I felt a strong, almost imperious urge to enter into contact with this resource for enjoying and living the moment... without judging – good, bad, well or not, it would be better if... none of that stuff, but just a raising of awareness. Now when the pains and regrets emerge – the dark things, so to speak – I don't send them away, but accept them, and this gives me a deeper sense of life, a greater value. To remove the pains of life at all costs, to deny them, also takes away its substance. Wounds, at the end of the day, are part of life's nutrition; they make it more substantial, richer. If we deny them, we also deny a part of ourselves... the idea of death does not frighten me so much any more... every story, every experience that speaks of death says the same thing: that those who have had a full and intense life die better. I say they definitely live better".
(Marina - Milano)

"...cancer is not just an "evil"; it can give you the chance to live a second life, a truer and more essential life, because you have the perception that your time may be brief and so you can and must do only the things that really count".
(Leda - Lugano)

"...I was a bit perplexed because I thought it was a ghetto... but from the first phone call I got the sensation that it wasn't. Then when I went over the threshold all my fears and worries vanished: the smiles, the joy, the great sincerity that shines out and the natural approach all make up an enrichment that is hard to explain if you haven't been there... here we talk about everything, we make plans, we work, we go on holiday, we get advice; here we say things that not even a

confessor has ever heard. When you go in you are small and fearful, but when you come out you are bigger and certainly stronger. From this experience I have discovered that we all too often live with our minds in the future thinking about what we will do, but without ever living the present, the only certainty that we all have, whether we have cancer or not”.

(Antonia - Lecco)

“...I just remember a great fear of dying: I had two small children and the idea of leaving them without knowing who would look after them drove me crazy. I joined the psychological support group and from then I began to see a ray of light in my despair. I remember, I remember my fear, I remember my companions too, I was afraid of them as well, I was afraid of hearing their stories, I was afraid one of them would die and I would suffer... but gradually I felt the fear of dying vanish: I realised it no longer took up as much space in my head. Before I saw everything in black, I imagined my own death and my funeral. Then I realised that life was starting to win, and in the end I became pregnant. I had to stay at home and rest but it didn't bother me; I was sure it would be a girl. I started making plans, and I felt happy. Before, when I heard people talk about tumours I was upset, but now acceptance makes me feel more alive... I look at my children and my baby girl... I make loads of plans that previously I never did. I'll be here, I'll be here for a long time yet”.

(Giovanna - Milano)

“...cancer on the one hand makes you think about the possibility of death, but on the other it can make you appreciate life more. It's paradoxical, isn't it? But precisely because that's how it is, you understand not to get attached to false things: just one more day is beautiful too... a friend asked me what my experience was like. I replied that cancer makes you face life rather than death... now I want to live in simplicity, in my daily life, and enjoy the little things!”.

(Margherita - Roma)

"...I was afraid of life, then the cancer came and it was not in the early stages. Through training my mind to accept the idea I might die, I freed myself from the fear of living. More than forty years have passed since I found my "friend inside" that helped me give every day a new meaning. And so I learned to give life to time and not just ask life for time".

(Ada - Milano)

Ada Burrone

Born in Fabbrica Curone in the province of Alessandria on 26 April 1933, she married at 20 and had a son; aged 36 she was operated for a breast tumour. In 1973 she founded the association Attivecomeprima, thanks to the support of her surgeon Pietro Bucalossi (then Director of the Tumour Institute of Milan), with the aim of improving the quality of life of people affected by cancer through human, psychological and medical support.

She is the author of texts on the management of psychological support groups. She is the editor and publisher of the magazine ATTIVE.

Among her writings:

“La terapia degli affetti” with Franco Fornari, ed. Attivecomeprima,
“Il gusto di vivere” with Gianni Maccarini, ed. Oscar guide Mondadori,
“M’amo non m’amo” (in Italian and English), ed. Pixel,
“La forza di vivere”, ed. Attivecomeprima,
“La danza della vita”, ed. FrancoAngeli.

Among her prizes and recognitions:

Cavaliere dell’Ordine “Al Merito della Repubblica Italiana” (1977)

International recognition St Rita da Cascia (1998)

Special prize Marisa Bellisario (2005)

Prize FAVO “Cedro d’Oro” 3rd day for voluntarism (2008)

Gold Medal of Benemerenzza Civica from the City of Milan
(Ambrogino 2009)

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Postscript

The unforgettable Mercedes Sosa used to sing *“Todo cambia”* - *“both what is superficial and what is deep change; our way of thinking changes; everything changes in this world.”*

In its detailed list of the things that change, the song does not include the upheaval that disease introduces into life, when we are suddenly forced to leave the safe land of health. *“Everyone who is born holds dual citizenship, in the kingdom of the well and in the kingdom of the sick. Although we all prefer to use only our good passport, sooner or later each of us is obliged, at least for a spell, to identify ourselves as citizens of that other place.”* (Susan Sontag: *Illness as Metaphor*)

A patient’s life changes superficially; but also the relationship between those offering healthcare and those receiving it changes deeply. The relationship between doctor and patient changes. This is not news: it has changed more than once over time. So much so that a historian of medicine, Edward Shorter, wrote a monograph entitled, *Bedside Manners: The Troubled History of Doctors and Patients*. One of the most spectacular changes has happened right in front of us, in less than a generation: the role of the medical doctor has radically changed. They were undisputed authorities and their authority has been questioned. Also legally: 20 years ago lawsuits against medical doctors were unusual; today they are commonplace. Medical doctors were revered figures with social prestige and moral authority – like a good father, or a good mother, they used to decide for their patients, choosing the therapy for them and managing the information in a way that allowed for a lot of reticence and even lying to the patient. Ever since the relationship between doctor and patient changed, we find forms for informed consent and extremely precise rules for the use of personal data, under the banner of privacy. Doctors and patients now risk being at best strangers and at worst enemies, holed up in their defensive positions (*à la guerre, comme à la guerre...*).

It is this kind of context into which Ada Burrone's letter to doctors fits. It is addressed to current doctors, and in particular to those who are going to become doctors tomorrow. The letter brings the good news of another possible change, a desirable change, or even more a change that has already begun. Ada acts consciously as a spokeswoman for this vanguard. She speaks about people – above all women who have been through the experience of breast cancer – who consider their doctor an ally and not a superfather to whom they can commit themselves blindly and passively, letting him lead them. And the doctor is not considered an insensitive professional, perhaps interested in unfair profit, from whom to guard oneself. The good doctor of today – and even more that of tomorrow – deals with the practice of medicine with the awareness that what is requested of him is of course “science and conscience”, but also listening to the person who faces the changes forced on them by the illness. Listening is the first step to correct information, which is not brutally poured down on the patient. In particular, listening is preparatory to the process of a shared decision, where both the doctor's clinical knowledge and the patient's preferences are directed towards the same goal.

In this way, the sick who look from the change they are going through grant the doctor their loyalty. If they are treated as adults – hurt, but not powerless, threatened by fear about their autonomy, but always called to *“keep their face against the wind”*, as the poet Saint-John Perse says – they will consider the doctor as a human being. They will respect the doctor's limitations, if the doctor has given evidence of his commitment. They will also forgive the doctor's weaknesses, if he does not hide behind the mask of a superman. They will share hope with the doctor, even when it tastes like hard and bitter bread, because the most human way to live hope is to share it. In Ada's letter the relationship between doctor and patient is something the Greeks called *“philia”*, that is to say “friendship”. Giuseppe Verdi was right when he said, *“Let us go back to the ancient times: that will be progress”*.

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Cover images.
Ada Burrone's portrait: Caterina Ammassari
Landscape: Getty Images

Print:
Tecnografica srl, Via Degli Artigiani, 4 - 22074 Lomazzo (Mi)
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