

“All need good vibrations, in a hospital bed”

Chiara M.

I wasn't well. The doctors kept coming and going, making decisions, peering, talking ... about me, but not "to" me. Everything happened in the morning, the time when doctors traditionally do their rounds. Then, in the afternoon, they would all disappear. The hours would drag by, in silence. But thoughts, of course, never ail. They come and they go and then they come back again, crowding the mind in a chaotic jumble. Seemingly simple, almost ordinary gestures, comments made in passing, eyes that glance in your direction, but never 'see' you. Voices would be heard in the corridor, drawing closer to the door, passing by and then fading away. Silence would fall again. A sense of bewildered loneliness would encroach on me, and my mind would become filled with questions, hypotheses, assumptions. Even though I don't believe in wizards and witches, if I had possessed a crystal ball I would certainly have looked into it to try and understand what was happening (From: "Crudele, dolcissimo amore").

When you are in the horizontal position, everything is different.

You have a different view of things; you are catapulted to the other side and find, with surprise, that things you experience in the flesh do not always fit neatly into a theory.

As a patient, one of the first things I immediately discovered was the enormous capacity patients have for observing and listening, especially for observing and listening to healthcare professionals.

You are stuck there, lying in a bed that is not your own, identified by a number, alongside people you don't know, thinking things that have probably never crossed your mind before; perhaps you face an uncertain future. The fact that you are in pyjamas is somehow debilitating, putting you in a position of dependence. You are very different from all that you were "outside". You are alone, and you have to fight your own corner. This is why, whenever you can, you listen hard and try to understand those who have your health in their hands, analysing their every action, their tone of voice, the way they move, and so on. Doctors' rounds are a case in point. You hope you are going to be given test results, or answers to the questions and doubts buzzing in your head, but above all you hope that you are going to have the doctor's attention.

But it doesn't always work out that way. I remember one occasion, during one of my first stays in a university hospital, when a whole team of doctors entered the room. They went rapidly from bed to bed. On reaching me they started talking 'over my head', battling questions and answers back and forth across the bed. I simply lay there while all this was going on above me, trying to work out when I would get my turn!

After the doctors' rounds are over there is visiting time, of course. The few words you received, those three or four minutes you were granted, get you thinking, and this leads to exchanges with the patients in

the other beds and with relatives. I recall another occasion – again as a patient – when, after the doctor's rounds, the other patients in my room started "dissecting" what had been said to them. "He said this, but perhaps he meant that, I didn't really understand, but you heard, didn't you? Do you remember exactly what he said? He seemed to be having an off day today ... I didn't feel able to ask him...".

Perhaps you too, in your experience, will have had occasion to observe that involving the patient in his own treatment plan, in ways that must necessarily be evaluated on a case-by-case basis, improves not only the doctor-patient relationship, but also the patient's mood. Patients' anxieties and fears very often stem from that fact that they are not informed about things that concern them. But it is not only clinical information that patients need. Even the simple and perhaps obvious actions or situations they may experience in the course of their care can be important too.

Sometimes, as a patient, it is nice to feel considered. And this feeling may be prompted by a look (he's actually looking at me!), a hand on the shoulder, a quick caress when you are enduring a painful procedure or when inside you there is a choking feeling of unhappiness that just will not go away. Of course it is easy to hide behind the excuse that there is never enough time for these things. But we are talking about giving the patient just fractions of seconds when drawing a blood sample, taking his blood pressure, changing his sheets, examining him, or simply bringing him a tray. If physical contact is not allowed or is inappropriate, you can at least give him a smile, a reassuring glance, a word. All this "gets through" to the patient. These are vibes that are difficult to explain, but they do get through.

In this regard, I wish to mention the American school of psychotherapy and the psychological research and treatment center in Palo Alto, which, researching the pragmatics of communication (this field of study concerns the effects of communication on behaviour), de-

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"A person among ghosts" by Marco Ceruti.

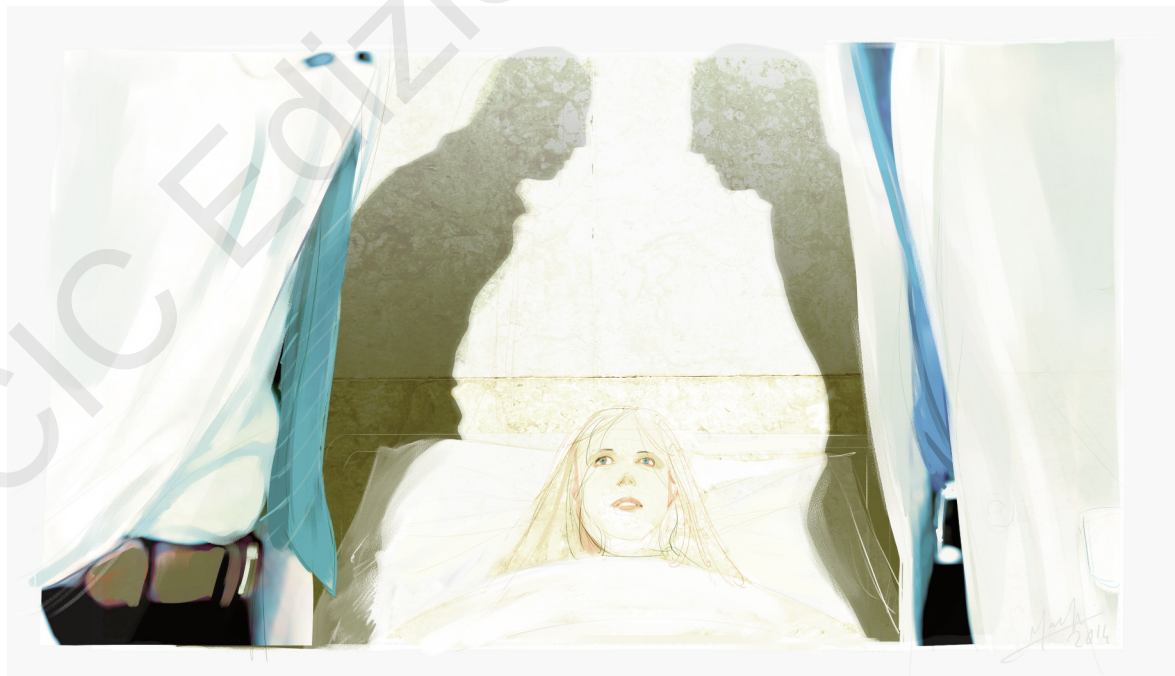
defined five fundamental principles. Two of these are:

1. One cannot not communicate.
2. Every communication has a content and a relationship aspect.

What do they mean in concrete terms?

The first principle means that when you come into contact with a person it is impossible not to communi-

cate with him or her. Since there is no such thing as non-communication, gestures, posture and metalanguage take on a precise meaning. If a doctor examining a patient confines himself to reading the patient's chart, asking him only essential questions and failing to make eye contact, he is sending out a very clear message of indifference: "You are one of many and I



"A conflicting discussion over me" by Marco Ceruti.

already know what you need". In every interaction, non-verbal language is far more powerful than the verbal kind!

The second principle highlights the fact that every exchange between human beings involves two levels of communication; in other words, a content message and a relational message. The content message is conveyed by the words themselves, while the relational message is underlying and constitutes the basis for the relationship. If a person looks out of the window while speaking, he is sending out two different messages. As a result of this discrepancy his interlocutor – in our case the patient – experiences a sense of (even latent) unease and discomfort. Instead, for these two levels to match, he (in this case the health-care professional) has to be open to the other, to lis-

ten, to be completely there, giving all of himself. When this happens, you, the patient, feel like a person, you feel heart warmed, and the loneliness you sometimes feel inside is tempered.

I have summed all this up in four lines:

Please look at me
Please listen to me
Please give me a caress
Please, make me feel that I exist ...

I have travelled all over Italy and also abroad, and I can tell you that pain is always pain, whatever one's race, language, colour, status and religion. It speaks one language and this is why alleviating it requires a joint effort.

A short biography of Chiara M.



Chiara loved the natural mountain environment and was a skilled guitar player when she first started working as a hospital nurse. Then, when she was still very young, she was struck by an incurable rare disease that progressively ravaged both her body and her appearance, forcing her to give up the things she loved the most. Because of her illness she had to stop working at the hospital and subsequently found herself obliged to use a wheelchair to get around and forced to come to terms with the fact that she was limited in her movements. During repeated hospital stays she began to view the healthcare world through the eyes of those on the other side, in other words to see it from the patient's perspective.

When still a young woman, she started writing as a means of recounting her inner world and expressing her desire to live and her efforts to find a meaning for the pain and limitations brought by her disease. Her first literary work is entitled "Crudele, dolcissimo amore"; first published in 2005, it has been reprinted in several editions. It is a sort of biography in which Chiara M. tells her story and reflects on her experiences with considerable personal depth but at the same time with a lightness of touch. She has since published other books – short stories, such as "La perla" and "Righe storte", and finally an intimate diary entitled "Oscura, luminosissima notte". This latter text provided film director Cinzia TH Torrini with the basis for a documentary film about Chiara M. in which the writer reveals some hidden facets of her ever-searching soul.