

Patient's Voice to Cancel Cancer: Autonomy for Patient and Oncologist – That Helps



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Inspire2Live has been created to empower people to convert the sense of powerlessness, caused by cancer, into one of strength. Inspire2Live is founded on the absolute belief that one can attain the greatest possible satisfaction by putting their heart and soul into helping others. Its motto is "Never, ever quit!"

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Let's start with a quip. When you want to become an oncologist, you only need three or four years of primary school. You need to be able to read and write. The pathologist will tell you what type of cancer the patient has, you can read in the protocol what to do, what the treatment is, and for the dose you need to know: 'Is it a man or a woman, what's her height and what's his weight?' Then you can plan the treatment and start. All set and done.

As previously said, this is a quip. Nevertheless, it is reality for many situations that patients and oncologists are dealing with. Sometimes I see that oncologists know that a treatment is not going to work but still given. 'It's in the protocol.' And worse, when a trial might be the best option, patients often still have to go through the protocol and only then can join the trial. Often, they are too fragile to participate and do not meet the inclusion criteria. Less than 10% of pancreatic cancer patients are in a trial. No wonder the progress in cancers like these is so poor.

We all know this is not the way to go. Patients do not want this and oncologists do not feel that they are really helping patients. In the Netherlands we're by far the best in protocolising medical care. We discovered regulation and gave it a new dimension. But we can do better. To quote the late Dr Jose Baselga at the Inspire2Live Annual Congress 2011: "We're not meant to be here for one or two months of life extension. We can do better." We can do better by bringing back autonomy to the oncologist and the patient.

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When dealing with a cancer as an unmet medical need, we have to explore better ways of treating. We have sophisticated diagnostics like sequencing to determine the genetic defect. And we can screen drugs. We have organoids, organ on a chip, different forms of tissue culture (when organoids are not possible) and we can use artificial intelligence for the right treatment. And most importantly, we can do this as a first treatment. Yes, we can. It is absolutely allowed when the patient and oncologist work together on this new way of treating patients. When the oncologist says honestly and clearly: "From the statistics we know that you can get one or two months of life extension if treated according to the protocol. I think we can do better if we tailor this treatment to your situation. We are not sure, but there is a good chance." And then, in this discussion, the patient can make their decision based on their situation and their perception of quality of life. As a matter of fact, we're not stupid when it comes to our own life; we can decide. Actually, we're the only ones who can make the right decision.

When dealing with patients and treatments this way, we learn. Of course, we document the treatment and the way the patient responds. Working

in such manner for a couple of years, we will see an enormous improvement in the outcome. Probably very soon, probably from the start of this new approach.

Precision Medicine is not a new treatment, it's another approach – with the patient at the steering wheel and the oncologist as a facilitator. Both with renewed autonomy that improves the outcome, which is the meaning of the work for the oncologist and the quality of life for the patient.

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