



Between Data and Emotion

In your lifetime, you will have a personal relationship with cancer. You may be a patient yourself or you will know someone—a relative, partner or friend—who is sick. Last November, a member of my family (I'll call him "K") was diagnosed with a rare blood cancer. His immediate reaction to this news was to educate himself, to gain knowledge through every source available. I joined him as his "co-CEO" in research. I have no background in medicine, and my studies in science stopped in tenth grade, but somehow, motivated by a combination of love and a high-speed Internet connection, I've learned to converse in the foreign language of cancer, using terms like *cytogenetics*, *RVD therapy* and *allogeneic stem cell transplant*. When I'm reading a clinical report and come across an incomprehensible phrase, I'm like a dog with a bone.

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As members of the 21st-century world of medicine, we are a population of caregivers and care-seekers that is accustomed to researching whatever we choose. We have access to resources that explain the minute details of a disease as well as the latest advances in its treatment. This is empowering, but it is also daunting. There's a deluge of data, both from the supporting resources (the Internet, oncologists, cancer foundations, support groups and clinics) and from the patient (X-rays, MRIs, PET scans, blood tests and biopsies). On top of that, the data is dynamic: the research is continually presenting new facts and figures, and so is the patient. The numbers are in constant flux, potentially steering life or death decisions.

The more information I collected for and about K, the more I felt the need to harness it. How do I, as his co-CEO, deal with the overwhelming volume of evolving data?

I called a very smart designer friend who knows a lot about information design and, more importantly, about me. I asked him for examples of software that would help me to comprehend, organize and track this explosion of material. He started to describe the workspace program Evernote and then stopped. He asked, "Are you approaching this problem as a researcher or as a family member?" His question was pivotal for me. He made me see that I had considered only half of the design problem. By focusing just

on the scientific data, I had neglected the onslaught of feelings that accompanies each new discovery. In other words, I had left out the emotions.

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Knowing that my approach to understanding most things is by engaging with physical space, my friend suggested that I set aside an actual place where the array of content could live; a place where I could stack it up or spread it out, but where I could also "close the door"—both literally and metaphorically—when I needed to. When we hung up I felt relieved, calmer, but with a sense of renewed energy.

Later that evening, I poured myself a glass of wine and walked around my apartment, opening each closet. One was filled with a disorganized jumble of clothes, books and folders, most of which had not been touched for years. I woke up early the next

morning and spent most of that Saturday emptying the closet. I piled up ancient and useless files, dragged them to the recycling bin, and then arranged to have the file cabinet hauled away. I tore out ugly plastic wire shelving and spackled the holes. I created a space that was pristine and white, ready for whatever it needed to contain.

On Sunday, I decided to look at the material that I had accumulated since K's diagnosis. The bulk of it lives within the more than 500 e-mails I've received. My plan was to quickly review my inboxes to make sure that I had kept important records. But I ended up rereading every e-mail, allowing myself to remember the impact of each one before moving on. As I went through them, I copied their subject headings—"FW: Targeted T cell therapy," "RE: Pain management team" and "Great news: Light chains are normal!"—and pasted each line, in chronological order, into a spreadsheet. Then I printed out all the pages, put them in a three-ring binder, placed the binder on the floor of the closet and shut the door.

In our dual role as researchers and loved ones, we are constantly trying to balance a seesaw. One side holds the scientific data, the other, our emotions. We need tools to deal with the heavy weight of both. [ca](#)

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