

November 2013

On February 7, 2007, I got up at 4:30 a.m. and ran seven miles before showering and going to work. In the middle of the day, I stopped in at my doctor's office for a routine physical because her office had been nagging me for months about how I was due for a check-up. Rather than procrastinating the routine blood work, I got that out of the way at the same time. I thought I would get a card in the mail a few weeks later and glance at it before throwing it away.

At 7:45 p.m. that night, I put my son in his car seat, and we left for a school gathering where the kids were going to do something cute in front of the parents. On the way to school, at about 7:55 p.m., my cell phone rang. I saw that it was my doctor so I picked up the phone. She said, "Get yourself to an emergency room. You're dangerously close to having a stroke." I asked her if I could call her back because this was not a good time to joke around. I hung up and arrived at school with my son.

We got out of the car and into the auditorium where I knew he was being looked after, and I called the doctor back. She made it clear that she was not joking and that I was in a perilous situation. I went into full denial, drove home and sequestered myself in my house with all the doors locked and shades drawn until a good friend talked me into doing the right thing. Within 24 hours I was in a sterile room at UCSF with a team of white-coated people trying to understand what was later found to be a very advanced case of Biphenotypic AML/ALL. Had I not been in strong physical condition I would not have made it to school with my son in the back of the car the previous night.

The smear of time that included signing waivers and agreements turned into about five months of in-patient living and the typical chemo/radiation protocol followed by BMT. At no point did it occur to me or any of the members of my support network to inquire about the lasting effects or potentially ongoing physical and emotional experiences that are often tied to the protocol and its components. Nor was anyone thinking about what life would be like after February 7, 2007, when it ceased to exist as it had for my life before my doctor phoned me that evening.

After the first month at UCSF, I was having a discussion with one of the other patients on Long 11, the floor where most of the Oncology and Hematology cancer patients were being treated. During this discussion, I was introduced to "the new normal" as a concept rather than the actual film. Because I was desperately trying to identify a way to conceptualize the drastic change my life was taking, I was attracted to the ideas being shared by this patient. At this point the struggle had more to do with accepting the physical nature of being that ill and the logistical difficulties related to having a small child I was not allowed to see for a month or more at a time, the prospect of not working again for a long while, losing a sense of productivity and purpose in the world.



David Weinstein

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A week or so later someone showed up in my room with a tape of *The New Normal* and set it up for me. I watched it two or three times in a row. At that time I knew nothing about the nbmtLINK and wasn't particularly curious, but when *The New Normal* was no longer a novelty, I started looking for more material and support mechanisms. It was then that I realized just how limited my preparation for my experience had been, and how naively blind I was to how my life was going to change as a result of the disease and the way the protocol affects life after treatment.

As I became more coherent later in the year and was made aware of the teleconference calls with the nbmtLINK, I signed up and participated in the programs that followed. The result is that part of this is actually the epiphany called "the new normal." There are numerous pieces of the physical, emotional, and spiritual changes that a transplant patient undergoes that will create or foster loneliness, depression, and periods of hopelessness.

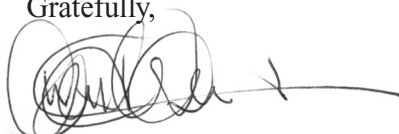
In hindsight, nobody with a white coat could have prepared me verbally for the changes and challenges outside of the actual physical disease, when the whole prospect was unwinding with such urgency and mystery early in the process. And though I firmly believe that preparation for post-transplant life is woefully under-addressed, the nbmtLINK is there when the need for support becomes clear to the patient. A sense of being part of a clan with similarly challenged fellow human beings was so welcome and overdue when I finally embraced the offerings. Teleconferences are only a small part of what the LINK makes available to patients. Other outstanding publications, the *Voices of Hope and Healing* quilt with its examples of creative expressions of joy, grief, loss, and relief are all part of this "family" of survivors that the LINK helps introduce. The website itself is a work of art and just a stroll through it offers solace. Without the host there would be no party of survival. Finding out that I was not alone in my experiences, my confusions, my breakdowns or quandaries was and is a saving grace.

One day my primary nurse practitioner was helping me dig out of a very depressed mood about a year post-transplant, and she said, "We {the University Medical staff} really don't like it when we work so hard and spend so much time, money, and emotional energy helping a patient survive only to have him give up trying due to a lack of post-treatment support." This said it all. Vital support and education services are available through the work the nbmtLINK does so efficiently and seamlessly. The depth that these resources manage to reach is truly impressive, given the LINK's very modest size, but so much more could be done and so many other suffering transplant patients helped—if greater financial backing was forthcoming.

It has come to my attention during the past few years that people who are given a chance to experience a "new normal" as a real life event quite frequently come to the age-old conclusion that in order to keep what they have been given, they have to give it away to someone else. Generally, those who are touched by the LINK and its resources do exactly that—so multiplying the impact will be the result of strong financial backing and contributions. There has never been a more worthy example of an organization that helps each client learn how to help themselves and another sufferer.

Please Support The LINK!

Gratefully,

A handwritten signature in black ink, appearing to read 'David Weinstein', with a long horizontal line extending to the right.

David Weinstein