

Using the Internet to Build Social Support:
Implications for Illness, Disability, Well-being and Hope

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When my friend Abby called my husband and me one Saturday night in April, I knew that it could only be bad news. Her voice was hyper-calm: as if emotion would splay her thoughts into fragments, like shrapnel through bone. And, good news can wait until morning.

Did we know how to arrange a medi-vac from Mexico to the United States she implored us, a question so out of range of our experience that contact and comfort had to be the sub-text. Moments before she had learned that her nephew, David Carmel -- a young man who had been one of the founders of Jumpstart, a national, non-profit organization training colleg-students to help preschoolers prepare to succeed in school -- had had an accident while diving into the waves in Mexico. On that April evening, she knew that he could not move his legs or hands, and that his sense of humor and compassion were intact. On vacation with friends, after his accident, he was still the consummate organizer. He had provided the phone numbers for the people he wanted called and suggested songs to sing while evacuating him from the beach.

My husband and I began making phone calls about the medi-vac. Superflously. An hour later, armed with numbers, we called Abby to learn that he was already en route to a hospital in San Diego.

I kept in daily touch with Abby about David, his family, and her experience. In July, I learned that David's friends had designed a web page for him. Intrigued, I went to my computer, logged on and was amazed by what I saw. His home page is sky blue... or ocean blue. It reads: "Welcome to the web page devoted to the energy, activity and spirit of David Carmel." Although I have since learned that it is not unique to create a web site for a person with an illness or disability, I had never before entered an interactive web site linking a seriously ill or injured person to his community. Traveling through it, I was flooded with reactions and feelings, among them curiosity about what had motivated whom to connect David and his friends by clicking on www.davidcarmel.com.

Subsequently, I spoke to a friend of David's, Jordan Meranus, another founder of Jumpstart, and learned that the idea of the web site had occurred a few days after the accident. A group of David's friends were sitting around an apartment brainstorming ways they could be helpful. People were calling each of them, wanting to be in touch with David, and wanting information about the accident and his current condition. A web site, they reasoned, could accomplish all of that and not leave David's family members or themselves exhausted from fielding phone calls. That night, they created a web development team and split up the various tasks. One of David's cousins, Jed Weissberg, a professional web designer, was drafted to create the site.

Entering the site, in addition to the welcoming words, a reader sees six links: Home, Photo gallery, Spinal Cord Links, Well Wishes, David's Progress, and Visiting

Soon. For me, they formed a natural path through the site. At the Home Page readers learn about the web site and the person who inspired it. The photos place David in his relational world. One finds pictures of David with family and friends, before and after the accident, as a child and a 26 year-old man. There are several links on the spinal cord links page connecting the reader to internet resources, including a stark web address: www.paralyzed.com, a site which "offers free information about: paralysis, spinal cord injuries, physical disabilities, resources for the disabled, accessibility issues, wheelchair resources, personal stories, mobility issues, people who are ventilator dependent, and more." Traveling there, so soon in virtual time after seeing the photos of David, I had a visceral reaction similar to the one I had when Abby first conveyed the news. Thinking of Susan Sontag's famous passport metaphor in *Illness as Metaphor*, I understood that ready or not, David was now traveling in the land where legs are not required.

The Well Wishes link provides readers with the choice to send a private message or one that can be read by other visitors to the site. In this way, community is formed around David -- with David, about David, and about people's efforts at revising their relationship to David. Everyone must change because David is changed. No one has the option of being in the same relationship to him. People's efforts at negotiating this change are both public and private here.

David's father, Peter Carmel, a neurosurgeon, wrote the section on David's Progress. It is an account of the accident from a purely medical stand point. It interdigitates with the two accounts of the accident that are also accessible on the web site by two of David's friends who were with him on the beach at the time of his accident. His father's careful, precise, easy-to-follow description of the injury, David's two

operations, and his likely prognosis allow the reader to grasp one of the many resources David has: his father's expert knowledge. At the same time, it is sobering and awe-inspiring to imagine oneself as a parent using one's expert knowledge on behalf of one's own child. I felt great compassion and empathy for Peter Carmel.

I skipped *Visiting Soon?* to read about "The Accident." The two accounts are riveting; they read like docu-dramas as well as eye witness accounts by trauma survivors. They are painfully vivid, rendering their scrupulously accurate descriptions of the accident as letters to David's mother, father and his two brothers the way one would offer a precious gift. The gift is a picture in words of the final moments of a David who can race to the ocean, exuberant and on his own.

As we would expect from two people who stood at different spots on this Mexican beach and were assigned different tasks in the crisis that followed David's dive, the two accounts merge and veer, affording views from different angles of the same event. In both David is the same: a pragmatic hero, inspiring by his ability to rapidly adapt to current conditions and be fully present.

For instance, from Jehane Noujaim's account; "...I sat next to him, and asked him if he hurt anywhere. He didn't, but he couldn't feel anything below his chest. The sun was beating down on him so we asked a young boy on the beach to get an umbrella. His body was shaking a little so I covered him with a towel and rubbed his hand and arm. I wanted so badly for someone to be there who would know exactly what to do, and understood what was happening. As if answering my thoughts, a paramedic arrived who I think was on vacation on the beach. He squatted next to David and introduced himself as

a paramedic. As each new person arrived to offer their help to David, David would answer with a warmth that was difficult to understand considering the circumstances."

Here is a snippet from Gregory P. Heyman's account, a few minutes after the paramedic has spoken to David: "...He was conscious and totally lucid. He definitely knew the severity of what had happened. David looked up and said, 'I wish I could just rewind the tape fifteen minutes.' I thought that was the essence of the human condition."

In these two devoted accounts, David is at the center, like a point of light from which the animating energy arises. In his stillness, there is an intense life force.

The final link provides instructions for those who may be visiting David. There is a system for ensuring he never has more than six (!) visitors at a time. More would overwhelm him and the limits of his hospital room. The motto of the page might be a phrase from it: "clean love is safe love." There are guidelines for visitors to follow to protect David from infection. While the page clearly takes care of David's needs, it also takes care of the first-time visitor's, making explicit whom to call, where to go, what to do upon entering, and what kind of gifts to bring.

I spoke to both David and his mother, Ann Carmel, about the effects of the web site on their experience. Ann Carmel spoke about the benefits to David. "The web site produced an outpouring from David's friends. He didn't have the strength to respond but it answered a question he had, 'Will people still be my friends if I'm in a wheelchair?' The web site answered that question. It said, 'Yes!' The beauty of the web site is that he can respond when he wants, when he is able. ...

"The two accounts of the accident were very helpful to a lot of people. They are remarkable descriptions. People understood from them the randomness of the event and

David's remarkable reaction to it. People who care want to know the circumstances, they want to know every detail of what happened without burdening David to get it. The descriptions allowed people to get all of that."

David Carmel was equally emphatic. "The web site has had amazing effects on me. It was a great way for me and my family to communicate with a lot of people. Most people don't really know what paralysis means. The web site helped people understand what happened to me, people I don't talk to daily, without it becoming complicated for me.

"I think the web site has been equally effective for people who are very close to me and for those who are more distant. Through it, I'm in touch with people in Zimbabwe and people next door. It's linked people from all areas of my life not just to me but to each other....

"I hope that the web site can be meaningful over time. I want it to be informational. We ran across an article in Scientific American, and we are going to post it on the web site. It takes work to keep up the web site and to have enough that's new on it that people continue to use it. The acute function was amazing. The task now is to make it meaningful over time."

Perhaps one way to make the web site meaningful over time is to get very clear about what its purpose is. David sees the purposes as those of informing and connecting. I might add another possibility.

In my recent writing on illness in the family (Weingarten, 1999), I have tried to extend my thinking about the nature of intimacy (Weingarten, 1991, 1992, 1997) to the nature of hope. Hope, I believe, is not only a feeling but something we do with others.

People can do hope together, and they often do so in community. The web site of David Carmel is an exemplar of "doing hope." It had a profound impact on me, one reader, in connecting me to a community where hope is being created, interaction by interaction.

As professionals who work with families in situations of acute and chronic illness, the implications for well-being of social support are well known to us. A web site provides a specific forum for a specific kind of social support, that which comes from participating in the collective practice of hope. In my way of thinking, the creation of hope is understood to be the responsibility of communities of people who care for each other. The internet is a vast, new resource for establishing and sustaining practices of hope.

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