Diary of a death

Families form online bonds as they share medical struggles

By Peter DeMarco, Globe Correspondent  |  November 9, 2004

Of all the things Steve Weissburg had to think about on the day his wife died of cancer -- funeral arrangements, his children's well-being, his immense sorrow -- sending an e-mail to a group of relative strangers might have seemed insignificant.

But when Weissburg got home to Cambridge that night, he turned on his Apple laptop, just like he'd done after so many exhausting days alongside his wife in hospital rooms and doctors' offices, and poured out his feelings to people he knew only as Meena and Vartul from Italy, Gail and Dave from San Diego, and Martine from Marshfield.

The group, all members of a "multiple myeloma" computer "listserv" to which Weissburg belonged, had followed every twist of Daria Donnelly's illness through her husband's numerous postings over two years. Kept abreast of her weekly white blood cell counts, her horror stories from invasive hospital procedures, and her 10-year-old son's progress in school, the listserv members had come to know Donnelly beyond mere words on a Web page.

As tired and sad as Weissburg was that night, he needed to tell the listserv that she was gone.

"I guess I felt that the [members] were important to me," he said later. "That even though I didn't know them, they were friends in a certain way, and I wanted them to know."

Date: Tue. 21 Sep 2004 19:29:57
Subject: Our Dear Daria has died

Dear Everyone, It is with utter sadness that I tell you all that our dear Daria, Mother of Leo and Josie, my wife of 15 years, died today. . .

Listservs -- electronic mailing lists in which e-mail "posts" are distributed to members for discussion or comment -- have existed for more than a decade, joined by people with a common interest in anything from politics to basket-weaving. Listservs for those coping with difficult diseases have grown quietly, without much public attention.

Many doctors regard these computerized chats as dangerous substitutes for the medical knowledge they provide patients. While most listservs have a "moderator" who monitors content, they can contain wrong or misleading information.

Still, more people than ever are turning to listservs for support, advice and information they can't get at the physician's office. According to Gilles Frydman, founder of the Association of Cancer Online Resources website, a clearinghouse for hundreds of listservs, about 200,000 people regularly log onto ACOR's various lists.

By next year, Frydman said he hopes to create a sister website with listservs for hundreds more diseases unrelated to cancer. And that would still be just one web site: Hundreds of independent listservs can be found on the Web for a variety of subjects, including Lou Gehrig's disease and even silicone implants.

The value of such listservs has never been quantified: University of North Carolina researchers are just now undertaking the first-ever study of the benefits of ACOR's listservs.

But listserv members tell stories of cyber communities with incredibly tight bonds.
Members of a listserv for stomach cancer victims once helped save the lives of hundreds of members by pointing out they might have been misdiagnosed and should take a new test to determine which type of cancer they had and what treatment they should receive, Frydman said. A distraught care giver from Brooklyn once e-mailed a suicide note to group members; one of those members called the local police, who found the man at home with a gun.

On a daily basis, there are less-dramatic but nevertheless meaningful interactions between listserv members -- applause for passing a medical exam, the scoop on a new experimental drug, poems, prayers, personal revelations, or just a word of encouragement when things seem at their worst.

"The clich is, of course, that misery loves company," said Bob Meyer, a San Diego resident and longtime member of the multiple myeloma listserv whose wife died of the disease in 1998. "But what misery really loves is understanding."

Date: Wed, 10 Apr 2002 17:07:09

Subject: Let me introduce ourselves

Hello, I just want to introduce ourselves to the list. My wife, Daria, age 43, was diagnosed with MM kappa light chain 2/13/02. She presented with back pain, Thanksgiving 01, followed by notice of a fractured vertebrae. It took over two months for the diagnosis of MM to be made, despite good care. Issues were somewhat confused with the fact that she otherwise felt great, and had given birth to our second child only 4 months before the fracture . . .

Steve Weissburg wasn't looking for a support group when his landscaper's secretary pointed him to the multiple myeloma listserv. He just wanted more information about this strange, nearly always fatal disease that was at tacking his wife's bones.

"I'm not into support groups and that kind of stuff," Weissburg still says, at home on a recent Sunday, his children's toys scattered about the floor. "I was like, 'I'm not going to do that. I don't have time. I learn from the doctors.' "

But it soon became clear to Weissburg, a 48-year-old patent attorney, that the listserv was more than just another Web site. Its members, well-versed in the jargon of the disease, could help him decipher mind-numbing medical reports. Drawing from personal experience, they could tell Weissburg how many days it would take Donnelly to resume climbing stairs after a stem-cell transplant, and other practical know-how doctors were less apt to provide.

Weissburg also could discuss things with listserv members that his own friends and family couldn't help with, such as how to talk to his children about the disease.

As he traded e-mails with members -- Donnelly never took an interest in the list -- he couldn't help but learn about their lives as well.

Just as in any physical community, multiple myeloma listserv members went on vacation, changed jobs, got divorced, had children, married, and sometimes got into angry spats that required other members to step in to restore the peace.

Certain personalities stood out, such as Meyer, the acknowledged sage of the list; "Aussie Pat" from Australia, one of its most down-to-earth cheerleaders; and "Boogie Barb," a longtime survivor whose endurance gave other members hope. Others, such as Dana-Farber Cancer Institute patient Richard Butts, who referred to himself as "the human lab rat," provided much-needed levity.

"Some people are ridiculously upbeat. 'Everything is good. God will save you.' That's not for me," Weissburg said. "But there were some people who really let you know what was going on. It's very helpful as a care giver to know: OK, this is the kind of life this person is living when they're having this kind of treatment. Whether it's good or bad, you know what to expect."

Date: Friday, July 30, 2004 4:32 AM
Subject: Daria mini allo day 84 GVHD liver

Dear Everyone, Again, just another short update. Daria is still in the hospital, and has been there for 10 days. Today things were a little better. . . . I took the kids in to visit her last night. We were there for about an hour, of which she spent about 25 minutes in the bathroom. But, that was OK. Leo helped get her tubes and electrical cords under the bathroom door, and Josie opened it up for her. Josie was so inspired, that she is trying the potty again today. . . .

Corresponding with listserv members from all over the world, Weissburg wrote more and more about Donnelly's resolve to live each day as normally as possible, and her boundless love for their children. He'd mention how Leo's teacher brought a tarantula to class, or how 3-year-old Josie dressed as a pumpkin for Halloween. Conversations about myeloma, though always important, often gave way to questions about scuba diving, or promises to meet "a year from now" for dinner at Durgin Park.

"There were times when I came home and I'd want to see what so and so said about my last post," Weissburg said. "There were about 40 people who were interested [in Daria] and maybe about 20 people who were very interested, some of whom I really liked writing back to. One was in Israel -- her father had the same sort of thing. One was in New Zealand.

"There was one guy who lived in Boston. He was at the Beth Israel and was always good-natured. I actually ended up visiting him in the hospital because we were over there all the time."

Date: Wed, 15 Sep 2004 15:35:08

Subject: Daria Update Home, but not Easy

Dear List, The weekend turned out to be very tiring for us all. We had more detailed conversations with Leo about the unpleasant course Daria's disease may likely take. That drained us all of energy and tears. Josie has been spared so far. Daria was visited by several friends, and telephoned by many more. It is really getting to be a strain on her. We are now limiting access for a while. . . .

Multiple myeloma has no cure.

Though some patients survive 10 to 15 years, the majority make it only five, with a rapid decline at the end as their bones and immune system break down. For some, the end can take as little as nine months.

Being part of the listserv meant facing this somber reality with every check of an in-box. And as the months passed, a number of people on the list whom Weissburg had befriended died -- the man he visited at Beth Israel; Aussie Pat; Butts, the human lab rat.

When Butts "died, that was really upsetting, because he'd been through the treatment that we knew Daria was gearing up for," Weissburg said.

In the spring, Donnelly underwent her second stem-cell-replacement surgery, this time using cells donated by her sister, Heather Annaloro, gambling on a riskier treatment that offered some promise of a cure. But complications followed almost immediately.

Weissburg said he and his wife didn't panic as the disease worsened. Donnelly was a patient woman -- "her fuse was infinite" -- who never lost the ability to laugh at herself, no matter how many times she'd been poked and prodded by doctors. Weissburg, who himself has undergone two brain surgeries to remove a tumor, is also even-keeled.

Still, unquestionably, he grew tighter with his cyber community as Donnelly's death neared. "From our house to your house," he addressed list members in an Aug. 12 e-mail. "Thanks for your continuing help," he wrote on Sept. 9. "Love to you all," he added six days before she died.

When the news finally came, the condolences flowed across the wires. And at least one member got in her car to make a more personal connection.

Date: Thu, 23 Sep 2004 23:11:53 EDT
Subject: Goodbye to Daria

Dear friends, Today, on a transcendentally beautiful day, I went to the "wake" that was held in Cambridge, Mass., for Daria Donnelly, Steve Weissburg's wife. I almost felt as if I "represented" the list (but perhaps others attended that I don't know about) . . . It seemed important to say good-bye to Daria, because I could. . . . It also seemed important to write to you, to tell you these people are really the way they seemed in Steve's accounts, that this has been an incredibly sad loss. I felt it more in their presence.

There were things about Daria most listserv members never knew -- that she was an accomplished writer and former Boston University literature professor, that she was editor-at-large of the Catholic magazine, Commonweal, that she boasted how her tombstone should read: "Never tasted a Coca-Cola."

Weissburg can't say just why so many people -- so many complete strangers -- became absorbed by Donnelly's story. Some certainly found similarities in their own situations, he said. Some simply liked his eloquent, spare, at-times witty writing style over someone else's. Some cared because it was hard not to.

While he intends to post news "every few months" about how he and his children are doing, he is also pragmatic. Now that Donnelly is gone, his interest in the listserv probably will come to an end.

"Over time, I'll post less frequently, and less people will know me," he said. "I think this list has waves of people who come and go. . . . It was nice to know that there were people who were interested."

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