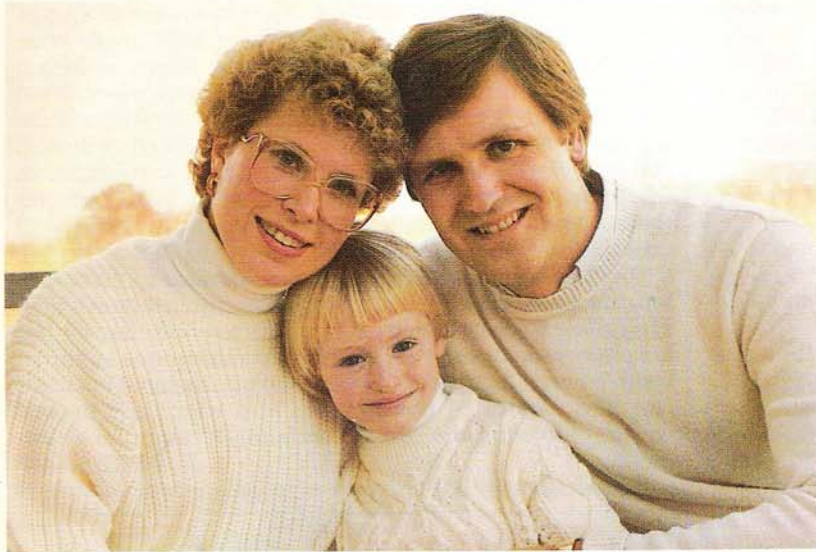# Family Crisis

BY SUE EDISON-SWIFT

Author Sue, her husband, Paul, and Annie

HOW ONE FAMILY BUILT A SUPPORT SYSTEM OF FRIENDS AND RELATIVES WITH ITS COMPUTER AND THE U.S. POSTAL SERVICE

SUE EDISON-SWIFT *is a technical writer, who lives in Middleton, Wisconsin.*

Our family computer has helped us manage the budget and the checkbook, but I'm most grateful for the role our computer played in helping us manage a crisis.

This story began last fall when our pediatrician found a lump in our daughter's abdomen. Four days and many tests later, we were given a diagnosis: Annie had neuroblastoma, a huge, inoperable, malignant mass.

Many people had the right to know this news. How do you tell family and friends that beautiful, 4½-year-old Annie would probably not live to see her sixth birthday? Repeating this news over and over on the telephone was not possible, and to ask someone else to make these calls was not fair. Since we have a computer system, we had another option. We chose to write a letter:

September 28, 1985

There is no way to say this easily. Annie has neuroblastoma, a large cancerous mass in the abdomen that has spread to bone marrow. Neuroblastoma is considered a terminal illness, treated but not cured with chemotherapy. Statistically, children with this kind of cancer are likely to survive less than two years.

We know you are devastated. We know that you care. For awhile though, please don't call us. We are hanging on by threads and would find phone calls draining, not supporting. We are good at delegating, and believe us when we say we'll contact you "if there is anything you can do." In the meantime, two kind neighbors have been elected to take calls. They have the latest information, and you should feel free to call them.

My husband, Paul, the computer enthusiast of the family, keeps an electronic address book using a data-base manager. Because this list is current, it was an easy task to select the people to receive the letter and print out address labels. In two hours, we had written, photocopied, stuffed, stamped, and applied labels to about 100 letters.

People complain about computer letters, but our family and friends were unanimously grateful to receive the news quickly—first hand from us. The one hundred letters generated an active support group of more than 1,000 people. Family, friends, and friends of friends sent cards and letters, mailed treasures to Annie, prayed for all of us, and did countless good works and kind deeds.

Happily, we had reason to mail a second letter seven days after the first. Annie's diagnosis had been made on the basis of several tests; the most important one was a bone-marrow biopsy. A hospital pathologist reviewed the biopsy slides and caught a slight inconsistency. As a result, an abdominal biopsy was ordered. Miraculously, the abdominal biopsy showed benign cells instead of neuroblastoma. It was unlikely, but suddenly there was a chance that Annie's tumor was not cancerous.

October 4, 1985

If the last letter we mailed you could have been entitled "despair," this letter can be called "hope." It seems there is a CHANCE that Annie has ganglioneuroma—the benign—not cancerous—mature form of neuroblastoma.

Surgery is scheduled for Wednesday morning, and the surgeon will try to remove as much of the massive tumor as he can. If the entire tumor is ganglioneuroma, Annie is CURED, and I can go back to worrying about the things most mothers worry about. If underneath this benign form of the tumor there is still neuroblastoma, then the prognosis is still bleak.

We are OK, in need of sleep, in need of more good news. Annie is a gift from God and is caring for us all. In the hospital playroom, she gives out her stickers to cheer up the other kids. "Don't worry," she told my friend Sibba. "I'll be all right." She gets scared and she cries, but she holds still and does what needs to be done.

The next time I write, I hope it can be titled "JOY."

Everyone on our mailing list liked the third letter best. Annie's football-size tumor was successfully removed and it was benign! It had been tricky, delicate surgery. It was a medical miracle. Our Annie was going to heal, and she was going to be all better.

October 14, 1985

JOY!

We have a miracle to report. On Wednesday, October 9, Annie's surgeon removed a football-size tumor from Annie's abdomen. He was able to remove 95 percent of the tumor which wound around, but did not invade, every

artery and organ in her abdomen (except the intestines). On Friday, the lab study proved that the entire tumor consisted of ganglioneuroma cells--the benign--not cancerous--form of neuroblastoma. This means Annie will be fine; she is CURED. No further treatment is needed.

The next letter mailed was a combination progress report, thank-you note, and holiday greeting. A letter timed for Thanksgiving seemed appropriate, for if any family had reason to be thankful, it was ours. Annie had healed quickly.

There were still worries. Annie's blood pressure had been elevated since her surgery, and her left kidney wasn't functioning at full capacity. We hoped both problems would resolve themselves with time.

Soon after Thanksgiving, it was clear that time was not helping. Annie would need a nephrectomy—her left kidney would have to be removed.

This time the surgery would be simpler and the prognosis clearer. Annie could easily manage with one kidney. We knew what to expect from surgery, and it wasn't anything fun. Annie returned to the hospital, and I returned to the computer, activating our support group once again.

December 5, 1985

Dear friends, once again we are asking for your help. Please pray that we be given the strength and courage to get through this. Please write us. Letters are concrete evidence of your concern, and they mean so much. Sending Annie "a little something" is always appreciated. Last time, the treasures she received did so much to lift her spirits and keep her occupied.

On December 19, we mailed our final letter. Annie's surgery went well, her blood pressure was normal, and she was recovering on schedule. *Have a merry, little Christmas,* I closed, *which is just what we intend to do.*

This story ended last year on Christmas Day, when we participated in a time-honored holiday tradition—traveling to Grandma's and Grandpa's house. My little girl had spent weeks in the hospital and had two major operations in two months. She was fine, and we were fine. It was a merry, little Christmas.

You see how our computer helped us deliver very personal messages. Paul's data base of addresses was used to help choose the families that would receive the letters, generate mailing labels, create a list of phone numbers to take to the hospital, and even keep track of gifts and kindnesses. Our word processor, spell checker, and grammar checker helped get the letters out. All of these things could have been done without our computer, but with it, the task was easier and faster. When managing a crisis, minimal stress and maximum speed are important.

Using the computer to write about Annie's progress had another, less obvious, benefit. Because we were essentially writing form letters, we could contact more people. Think of the important people in your life that you see or write to only occasionally. These were the

CREATE AN ELECTRONIC ADDRESS BOOK

Keeping an electronic address book is a nice way to integrate your computer into your life. Medical emergencies aside, you can use a single data base to: 1) make current address lists for invitations, announcements, and vacation postcards; 2) generate mailing labels; and 3) print out Rolodex cards for a computer-generated address book.

We keep our address book in *dBASE II* (Ashton-Tate). Each address is entered using this format.

LAST NAME (25 CHARACTERS)	*This is used for alphabetizing.*
FULL NAME (34)	*Entered as you want it to appear on a mailing label.*
ADDRESS LINE 1 (34)	*We limit the address fields to 34 characters so it will fit on a mailing label.*
ADDRESS LINE 2 (34)	
CITY, STATE, ZIP (34)	
PHONE 1 (25)	
PHONE 2 (25)	
PHONE 3 (25)	
CODES (10)	*We use codes to help select subsets from the data base. For example, C = Christmas card list, B = Business, F = receives all family mailings. A temporary code here will let you print out just the new entries.*

Using *dBASE II* and *WordStar* (MicroPro), you can print out Rolodex cards for each entry. Making multiple copies gives you access to current addresses and phone numbers everywhere you need them . . . by each phone, on the desk, or at the office. When crazy Aunt Sophie moves for the 20th time, you just enter in the new address, print out four new Rolodex cards, and everything remains neat and current (2¼" x 4" Rolodex cards are available at a stationery store as a continuous form for your printer for about $17 per 1,000 cards).

people especially touched when we included them. In fact, some of the most comforting letters and greatest help came from people on the periphery of our lives. We wouldn't have had the time or strength to contact so many people any other way. A mass mailing allowed more people to be involved, to help, and to show they cared.

One year later, Annie's only apparent scar is the one spanning her tummy. Annie is a bright, happy, funny kindergartner who wants to be a singing-mommy-doctor when she grows up. The close of last year's Thanksgiving letter still rings true:

We are fine, the three of us. We learn from Annie how to put some of this experience behind us and some of it ahead of us. Instead of counting blessings we will try to use them. And we will always remember how the love of God, our love for each other, and the love from all of you, saved us. Our best wishes for happy holidays and a new year filled with joy.

It's time for me to power up the computer and write my 1986 holiday greeting. It will probably be dull when compared to last year's letter. I don't think anyone will mind. **rc**

A MASS MAILING ALLOWED MORE PEOPLE TO BE INVOLVED, TO HELP, AND TO SHOW THEY CARED.