

E-mail from a Website Visitor

"My mother (age 79) began experiencing shortness of breath about 1 week ago. The hospital ran tests suspecting 'heart problems'. They found nothing and planned to release her even though she was having increasing episodes of breathing problems.

"I thought I would just scan the Web to see what I could learn. I did a search on the keywords 'shortness of breath', which took me to your site. I read the case history there and the testimony of other pulmonary embolism patients.

"There my mother's symptoms jumped out at me. She had hip replacement surgery 6 weeks ago. Many of the cases described were postoperative incidents. I found out about the required V/Q scan from your site and sent the info home to my sister in [the Midwest]. I live in [New England]. She was able to ask the nurses specifically if my mom had this test. They said no.

"My sister had asked the doctors repeatedly if it could be a blood clot. They said no. It was too long after the hip replacement.

Needless to say we got her to another hospital where after describing my mom's symptoms they immediately performed the V/Q test and guess what they found. Clots!!

"I know this has been somewhat long winded, but I wanted to let you know how much I appreciate your efforts in getting this info out on the Web and into the hands of the public. I feel you had a part in helping my mother by giving my family the information we needed to pursue the problem and become empowered. Otherwise, my mother would have been a ticking time bomb waiting the 10 days the original doctor told her to wait before she returned for follow-up.

"So, if you ever wonder if your site is being visited and if it helps anyone, I can emphatically say YES!!!"

I do often wonder whether the effort and expense invested in institutional Websites (especially those of not-for-profit institutions) can really be justified. So receiving this

letter was a pleasure I had to share with all of you. Our site is based on case studies, and our intent in sharing this rich resource with the world is to provide our interesting material to trainee and practicing physicians. The part of our site that this writer accessed is clearly marked as being written for physicians, and we have occasionally discussed the wisdom of placing such material where it is easily accessible by patients and their families. Not all patients use medical information in the intelligent, thoughtful manner exhibited by the writer of this letter. But obviously some use it to great advantage. So, on balance, is there a lesson here about the value of allowing all people access to information so that those who can make profitable use of it have an opportunity to do so? I think so. What do you think? Let's chat! sedwards@ulna.bwh.harvard.edu.

"CBE InterViews" and "The Word-Watcher" will be back in the next issue.

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