



TWO BROTHERS fighting Lou Gehrig's disease.

Q & A

Stephen Heywood

The remarkable story of Stephen and Jamie Heywood, both from Newton, has captured national attention, including last year's book *His Brother's Keeper: A Story From the Edge of Medicine*, by Jonathan Weiner, now out in paperback. Stephen Heywood was 29 when he was diagnosed with ALS, better known as Lou Gehrig's disease, a progressive muscle-wasting illness that is usually fatal. Jamie, his MIT-educated brother, dropped his technology career and founded the ALS Therapy Development Foundation in Cambridge, which has raised \$20 million and has two drugs in trials. Stephen, now 36, who lives with his wife, Wendy, and 4-year-old son, Alexander, has lost the ability to talk, breathe, or eat on his own. He communicates through a computer by moving his head.

What's your prognosis? There is really no prognosis for patients in my condition. The last thing I'll lose is communication. Unless I have an accidental death, I'm shooting for a normal lifespan.

Many ALS patients live only a few years after diagnosis, yet you're well into your seventh year. Whom or what do you credit? Nothing and nobody. I don't believe patients have any control over progression. I have made choices that keep me alive, such as a feeding tube, a [ventilator], and a communication system.

You've described yourself as "basically a quad with a ragtag collection of muscles surviving," a reference to the TV show *Battlestar Galactica*. How do you keep your spirits up? A little Prozac and alcohol. People keep the same outlook in good times and bad. Also, even with ALS, my life has been easier than most.

Do you believe there has been some purpose to your disease? I don't believe in fate. But I know Jamie will cure ALS, and perhaps other diseases, whether I'm alive or not.

Are you preparing your family for your death? No. Last night, I watched Alexander sleep and swore I would not die. I stay alive for my wife and child.

- Elaine McArdle

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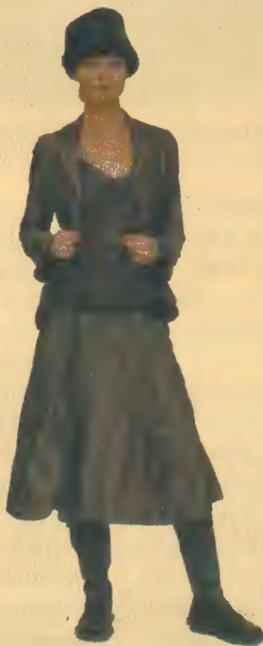


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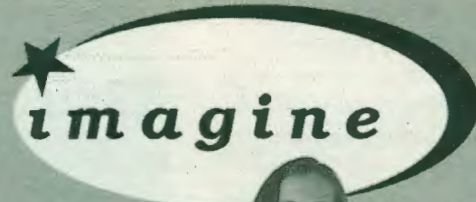
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