The following is taken from a recent blog posting by Scott Stafne, a young husband and father of two. He wrote this on the five-year anniversary of his diagnosis with Amyotrophic lateral sclerosis (ALS, also known as Lou Gehrig’s Disease):

My arms and legs are nearly useless, although my legs can still bear weight, and my right hand can drive my wheelchair. I need help with just about everything, and can rarely be alone. Lately I have struggled to make this choice, but today I choose to celebrate and rejoice in the myriad ups and downs of this journey. I am fortunate for all of it.

I briefly met Scott, a software engineer, not long after his diagnosis and check in on his blog from time to time. This post would intrigue anyone in our profession (visit http://stafnes.com/blog/archive/2009_04_01_archive.html). It addresses all of the effort and engineering it takes to make him comfortable reading in bed each night.

Scott identified nearly 20 items that are necessary to help him read in bed. Items include an arched reading lamp with a pivot disk that will allow it to swing out of the way when he needs to be gotten in and out of bed; a lap desk; a book with pages firm enough for him to grasp and turn without ripping; a hospital bed; and a catheter bag.

Some items were simple to assemble, like the pillows that support his arms and head. Some required effort, like the rolled piece of tape with just the right amount of stickiness stuck the wrong way out on his finger to assist with page turning, and the long straw crafted from plastic tubing that brings water from a large pitcher up to his mouth. Some items changed over time as his abilities changed, like the bed remote that now has small non-skid, stick-on rubber bumpers on the “down” button to make it easier to push.

Scott concludes:

We’ve engineered this one process, reading in bed, hundreds of times. We’ll continue to innovate until I can’t turn the pages, and then we’ll need to solve that riddle too... Something’s changing every day, every month—we need new solutions, new strategies, new capabilities to make this one thing doable. But it’s worth it to give me one of the most normal feelings I have all day.

While most illnesses do not present the home care challenges of severe neuromuscular disease, reading an account of addressing this one basic activity for a person living with ALS helps to illuminate aspects of how home care differs from hospital. Among them is the stress on the non-professional caregiver. It can be easy to focus on the person who is sick and the technology that surrounds him or her, forgetting that others are there as well. But
keep in mind that behind every item in Scott’s account are the efforts of his wife, Kirsten.

Primary caregivers are usually close family members, and that stressor alone differentiates them from most professionals. Some are parents of small children, some have to work outside the home to continue to pay the bills, and all have to care for themselves as well as someone else. Their responsibility for and concerns about their loved one’s care do not end at the change of shift.

This issue of Horizons deals with technology applied to home healthcare. When I think about care in the home, while I find it useful to be informed by my professional experience, I try to be sensitive to the differences in the overall caregiving environment. For example, consider the issues associated with user training, device malfunctions, and use errors when applying technology in the professional setting; now imagine them in the home for a non-professional caregiver dealing with a lot more than just giving care. Add in other non-professional caregivers who take over for the primary when he or she needs to sleep, to work, to care for others, or respite for themselves. When developing technology for caregiving in the home, who is caring for the caregiver? What tools are being developed to help them not only deliver care to their loved one, but also to themselves?

My experiences outside the workplace have awakened me to realize that in addition to addressing illness, healthcare is (or should be) just as much about making living possible. I am reminded of words inscribed in a hallway at Massachusetts General Hospital: “the secret of the care of the patient is in caring for the patient.” Given the slow but steady movement of caregiving away from the hospital to the home or other non-acute setting, I would suggest that motto needs to be extended to include caregivers, especially those whose living is intimately entangled with the person receiving care. Our development and management of technology for home care needs to take this into account.

What tools are being developed to help caregivers not only deliver care to their loved one, but also to themselves?