

# Time to Teach the Doctors

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*Literacy levels in the United States are alarming: 25 percent of the public cannot read the headlines of a newspaper and 48 percent cannot decipher messages with words and numbers. Studies on the impact of low health literacy (defined as the degree to which individuals have the capacity to obtain, process, and understand basic health information and services needed to make appropriate health decisions) reveal that it may cost the United States health care system up to \$200 billion annually.*

*Read one patient's story with her own literacy challenges and some practical strategies she offers that any practitioner can use to improve the safety and reliability of care.*

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## Time to Teach the Doctors

By Norma Kenoyer as told to Cindy Brach

I'm Norma Kenoyer, and I've lived in Iowa all my life. I'm 66, and getting older. I don't read that well. My brother doesn't read either, and neither did my dad. My mother could read and my sister reads. I went to school through 9th grade. All through grade school they read to me; I didn't have to do any work. I wish they'd made me read. In middle school they gave me books to read and I couldn't do it. I went home sick. That's when I started having migraine headaches. It was just hard for me to do schoolwork, and so I got my friends to do it.

I enjoyed school. I loved school. I wanted to learn but they just did not teach me. When they told me that I could not go to high school because it would be too embarrassing, because kids would make fun of my reading problem, I cried like a baby. I wanted to go to high school so bad.

Instead I got married. My husband left me when my third child was two weeks or three weeks old. I was 20. I knew it was very important to read to your children, so I would make up stories to go along with the pictures in the books. My children didn't even know I couldn't read until they got up into the higher grades in school.

My parents hardly took me to the doctor's at all, unless I was half dead, like when my appendix broke. But I took my children for physicals; I was very good about that. If I had an appointment for my youngest son, I'd take my oldest son out of school so he could help me fill the papers out. I didn't want to tell anybody that I couldn't read the papers.

If I couldn't bring someone with me to the doctor's to fill out the papers, I would just fill out what I could. Mostly it was my name, address—that's about as far as I could get on those papers. Then I would just check off the boxes asking if I have these diseases. I would just guess at it. Once the doctor said, "Oh, you've got diabetes." "No, I don't have diabetes," I said. And he said, "Well you marked it here."

I wish the doctor had asked if I wanted to improve my reading and given me some information about a program. I looked and looked for a school to go to, and I couldn't find

anything. I was searching probably for 15 years trying to find something.

A couple of years ago I had a colonoscopy. They took bumps out of my rectum. After the procedure they gave me some papers, but my husband rushed off to work and didn't have time to read them. They didn't tell me, "You take it easy the rest of this day and take tomorrow off." They just gave me the papers, and said, "Have a good day."

Anyway, I went to work. I was helping this lady move, and I was picking up heavy things. The next day I woke up and felt like my insides were going to fall out. I was in a lot of pain because I should have stayed home. And I had a little bit of blood that wasn't supposed to be there. Then my husband read the papers to me and tells me I'm supposed to stay home and relax. They listed things you're not supposed to do and it said definitely no lifting. So it was just a lot of problems I wouldn't have had if I'd stayed home just one day.

I never did call the doctor about it. I probably should have, but I didn't. And I wanted to tell him about my reading problem but I was still scared to do it. I don't know why I was scared. I'm sure he would have understood.

I just don't like doctors. I know they're there to help me; they've saved my life a couple of times. But every time you go in the office, they hand you a bunch of papers to fill out. I'm sure there are other people that haven't gone to school and they're the same way. I've seen it a lot of times when I'm in the doctor's office. There was one guy that got very angry and I knew he couldn't read. He said, "All these blankety-blank papers you give me to fill out!" and threw them down and left. A lot of people use anger to hide it.

Even at the pharmacy they hand you papers. When I first started taking my blood pressure pills, I asked, "What's inside of that?" I didn't want something that I'm going to take to give me side effects that I can't handle. They said, "Here's a paper ... it tells you." So I said, "Well I'm not a very good reader and it's so tiny I can barely see it." So they went over it with me.

Nowadays the papers at the doctor's office are much easier. The lettering is bigger. I was at the doctor's office today. When I was filling out the papers I figured out most of the words, and I could not do that before. I was in kind of a quiet place. That helps with keeping you calm. When I started getting nervous I said to myself, "OK, Norma, you can do this." I talked through my fears. And finally I filled most of it out until I got to pregnancy; I did not recognize that word and a few other words. When I filled out all that I could, the nurse took me back and helped me fill out the rest. I said, "Hey, I'm not a very good reader. Can you help me with this?" And she was very eager to help.

Before, my doctor just seemed like he was in a hurry. I read his body language. He'd ask if I had any questions, and I said no and he'd walk out the door. I could have asked him this and that, but he couldn't even give me a chance. It was, "Any questions?" and out the door he went before I could even think.

I was just about to change doctors, but I said, "I'll try him one more time." The day I gave him the "[Ask Me 3](#)" brochure he spent about two hours with us. The receptionist needs to learn not to pack the appointments so close together.

I've been seeing the same doctor now for a year. Two weeks ago I went in there real brave and I told him I had trouble reading. He was very interested and very surprised. He asked,

"How do you manage? What do you do when you're given information on paper? You need to know this information." I said I realize that. I told him I was in a literacy program and was learning about how to ask questions, how to work with doctors, and how to fill out the papers.

When I told my doctor about my reading problem, I was more or less teaching him how to work with us, people with reading problems. I said, "I know it's the biggest problem; that's why there are so many people sick -- because they don't understand. You don't understand us and we don't understand you. And that's why I'm telling you about this." I also told him some things he could do to help. I said if you have patients' addresses you can send them the papers to fill out ahead of time. They can have their spouse or someone in their home fill the papers out and send them back to you.

I also told my doctor about teach-back. When a patient's on medicine, you need to show him what to take, how to take it, and when to take it. You have to be specific. Like tell him take it once in the morning, like 9:00, and once in the evening, either 9:00 or 10:00. And then tell them to teach it back to you. There's a lot of people, even readers, who don't know how to take their medicines.

If the doctors know you're not a reader, they need to share that information with the receptionist. Then the receptionist could ask, "Would you like to have help filling out these papers?" That would be a load off my mind. Or if you don't know whether the person can read you could just have your receptionist look and watch the person, see if he is holding the pencil tight or taking a long time to fill the form out.

Forty years ago I didn't want to tell anybody I couldn't read because they didn't understand back then. Today they're more understanding; there's been a lot of work to help the doctors help us.

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