

# THE PREPARED PATIENT

## When Getting to the Doctor Is Half the Battle

For older patients, particularly those with a disability, the path to the doctor's door may be filled with stumbling blocks. Without help from friends and family, assistive and accessible technology and medical offices that comply with disability law, these patients risk falling behind in their health even before they reach the exam room.

Thomas Hainze — an 84-year-old Texan left voiceless by laryngeal cancer — uses a combination of family and technology to solve his appointment challenge. His daughter sometimes makes the calls for him, or he logs on to his “My Chart” profile to schedule the next visit by e-mail, “which has certainly made things easier for me,” he says. At University of Texas Southwestern where he goes for care, patients can use their My Chart online medical record to make appointments, view their lab results and remind themselves of their medications.

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“How do you balance that clipboard on your lap when you have rheumatoid arthritis?”

—June Isaacson Kailes, disability policy consultant

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Recent studies suggest Hainze is not alone among older patients in using the Internet to communicate with their physicians and look up health information, as the digital divide between younger and older Americans that existed in the 1990s begins to close. “But not all Web sites are created equal when it comes to things like text size, ease of navigation and compatibility with assistive technologies

that can help disabled users,” says David Baquis, an accessibility specialist with the U.S. Access Board, an independent federal agency devoted to accessibility for people with disabilities.

“Before patients call to set up an appointment for the first time, they may check the Web site of their insurance company to select a provider, such as a medical specialist,” he explains. “But if the Web site is not accessible, then they may not be able to read it or interact with it.

Phone trees or answering services can be a specific problem for patients when they are unable to press a button to reach a live voice, Baquis says. He notes that the federal government has drawn up specific standards for accessible voice mail and interactive voice menus for people who are deaf or speech impaired to use with TTY— text telephones — used to type and read messages over the phone. Some patients with memory problems may also use TTY to keep track of important phone numbers and

### HEALTH CARE OBSTACLE COURSE

#### Common barriers for people with disabilities include:

- Making appointments by phone
- Hard-to-navigate health Web sites
- Transportation
- Undergoing exams or tests
- Filling out forms
- Communicating with the health care team

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conversations with their doctors, other studies have shown.

Then there's the question of what to tell the doctor when the appointment is scheduled. Should you tell the scheduler that you have a disability, even if the disability is not the reason for the visit?

"It's not necessary to tell them unless you have a need that you have to take care of right up front," says June Isaacson Kailes, a disability policy consultant in California. "But some things are so important that you need to tell them before, the day of, and right when you go in, like if you're having a mammogram and you need two techs to help you effectively use the equipment."

Some patients may prefer that their doctor know about their disability from the beginning, as a way of gauging the physician's ability to meet their care needs.

Hainze's good health helps him navigate the next step toward his visit. "I usually drive myself to medical appointments unless I am physically impaired due to a severe attack of anemia," he said. His mobility is the exception among his age group. Older patients in poor health, especially those living outside urban areas with public buses and trains, are more apt to stay home or risk driving with poor eyesight, according to researchers.

Once they arrive for their appointments, older patients and patients with disabilities are increasingly finding accommodations such as accessible parking spaces, curb cuts and waiting rooms big enough for wheelchair users, thanks to the federal Americans With Disabilities Act. But there can be less obvious obstacles inside the office, says Kailes. For instance, how do you fill out the forms handed to you by the receptionist when you have macular degeneration that makes the words a blur? Or balance that clipboard on your lap when you have rheumatoid arthritis?

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-- *David Baquis, accessibility specialist with the U.S. Access Board*

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Don't be afraid to speak up and find out if there's another way, Kailes urges. "You can say, 'I'd like to get forms mailed to me, so I can fill them out where it is easier for me to write,'" she suggests. "Or you can ask for help in filling them out. Or, you can find out whether you really need to fill in their forms or just come ready with a copy of your own records."

"The biggest challenge for me at medical appointments is to try to be prepared with written information to present the doctor to avoid wasting his or her time," Hainze agrees. "I also write relatively rapidly and clearly using a small marker board to respond to specific questions."

Haize doesn't usually bring his daughter or other family members to his appointments. But Kailes thinks a companion can be a good idea, as long as it's made clear that the doctor should speak directly to the patient and not the partner—a complaint among some patients with disabilities.

Doctors sometimes "assume that they [the patients] are stupid or frail, or can't work or don't work, or that they're unable to take care of themselves," Kailes says.

In fact, a lot of accessibility boils down to "good customer service" and thoughtfulness, according to Baquis. "Let's say the office assistant writes down the date of my next appointment real small on the back of a business card. That might be hard to read if I have low vision," he explains. "And it's not that hard to use a thick marker and write the information on a separate piece of paper for someone."

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And patients can nudge their physicians to make these little adjustments. “If you’re deaf, or hard of hearing, just say, ‘I read lips, please look at me, and keep your hands away from your mouth.’ Or tell them, ‘My speech is slow and it’s hard to understand, so please ask me questions if you don’t understand,’” says Kailes.

“It should not be assumed that all scenarios related to providing accessibility are difficult and expensive,” Baquis adds. “Attitude can be the greatest disability barrier.”

## RESOURCES

The pamphlet *Making Health Care Work for You – A Resource Guide for People with Physical Disabilities* can be downloaded in a several formats, including Braille-friendly, through the Web site for the Center for Disability Issues and the Health Professions:

<http://www.cdihp.org/products.html#prevent>

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