

## **Women's Health Perspective: The Importance of Attitudes in Caring for Women with Disabilities**

This material was written by an adult woman with blindness, based upon her real-life experience. It is intended to provide module users with insight into the patient's perspective, and provide guidance for improving patient-centered care.

### **My More Negative Early Experiences**

My experiences with gynecology appointments as a person who is blind vary from having feelings of considerable anxiety to more recent experiences that have been satisfactory. When I had to start using birth control pills, the doctor explained how to use them, but never explained to me about the other precautions I would need to take if I did become sexually active. The doctor I had as a teenager communicated with me only when he had to. I had to ask questions, and sometimes I would ask my mother to come in the room for a sense of security. The doctor and office staff never inquired or listened very well when providing assistance to a blind person like me. The receptionist would speak to my mother instead of me. My mother would insist that I could speak for myself.

My first Pap smear was the most difficult. Since I did not like my doctor's "bedside manner", I asked if the nurses could be in the room while the procedure was being performed. The nurses were more understanding of the fact that I was blind, and let me check out the instruments used for the Pap smear. However, the nurses did not explain possible infections or what caused them; they just said that I had an infection, and prescribed a cream. My mother and I had to figure out the best way to use the medication.

Neither the nurses nor the doctor asked me questions related to my sexuality. The first time I was ever approached about this subject was when I had my appendix removed. The nurses in the hospital at that time treated me as an adult, but I was a little embarrassed and caught off guard when they asked personal questions. They did not prepare me first by saying, "Would you mind answering a few personal questions?"

When I was 18, I had to have a cyst removed from my breast, and I was frightened of what the results would be. I was not frightened of the exam itself, although it was discomforting. The nurses at the hospital let me check out the equipment. The medical staff was more understanding about asking questions and approaching the subject of treatments I would need to think about if the cyst was not benign. Disability was never an issue. In contrast, the doctors and the staff at my home clinic had let my disability overshadow their treatment.

### **More Positive Experiences**

After I married, I moved to another part of the state. There I found that my experiences with healthcare were completely different. The doctor and staff were much better at providing assistance, explaining infections, what to do, and were not afraid to approach personal subjects. They would, of course, let me know beforehand that they were going to ask about personal

information. My former health care providers either never communicated unless probed - or just came out and asked personal questions without preparing me.

On the other hand, my new providers **wanted** to know more about providing assistance. They talked **directly** to me, rather than avoiding certain subjects or talking to the other people in the room who came with me.

For example, when I had my breast exam and Pap smear, they asked me questions about college and what I wanted to do about having children. They explained to me about fertility tests, and during the procedures asked me if I was okay. They would even make jokes to me about difficulties they were having in getting to certain organs to test! They only hesitated to perform a breast exam because of my young age. Disability was not the issue, but they were thorough and wanted to know an exact history of why I insisted on having a breast exam. This is how I hope all health care providers will treat women with disabilities, as we seek the health care that we need, which is really the care that all women need.