

**GYN Exam & Mammograms  
for Women with Developmental Disabilities  
by Sharon Witemeyer, MD**

The vast majority of women who have been diagnosed as having a developmental disability, have normal feminine anatomy, normal female endocrine function, and normal breast development. There are some exceptions. Women with spina bifida frequently enter puberty early. Some women with central nervous system malformations, as a result of genetic, congenital, traumatic or postoperative abnormalities, may have pituitary dysfunction. Reproductive endocrine disorders occur more frequently among men and women with epilepsy. Individuals with developmental disabilities are at greater risk for developing thyroid disorders than the general population. Use of anticonvulsant medications in this population may be associated with ovarian dysfunction.

Women with developmental disabilities are at a higher risk of sexual abuse than the general population and this presents the potential for increased rates of cervical cancer. However, most women who have a developmental disability have normal reproductive health histories. Like all women, they are at risk to develop cancer of the breast, cervix and ovary.

Many families and physicians have been reluctant to provide routine gynecologic health maintenance to these women. There has been a sense that they could not tolerate breast and pelvic examinations that it would be too traumatic for them, take too much time, or simply be "a waste of time". Like all of us, women with developmental disabilities need and deserve the highest standard of medical care available and this includes reproductive health surveillance.

Recommendations for routine gynecologic examinations and mammograms for women diagnosed with a developmental disability follow.

**Pelvic examinations and Pap smears:**

First pelvic examination with Pap smear when the patient becomes sexually active or at age 18 years. Annual pelvic examination with Pap smear every three years. If the patient has three negative Pap smears, then Pap smears can be done every two years, perhaps even every three years. (The problem with increasing the interval between Pap smears is that many women will not return for a routine annual pelvic examination and ovarian cancer may be missed.)

**Annual pelvic examination.**

- Annual pelvic examination and Pap smear after age 40 years.
- Breast examinations and mammograms:
  - First breast examination at 18 years and annually thereafter.
  - First mammogram at age 50 years.
  - If there is a family history of breast cancer in mother, sister, daughter, or two close female relatives or known genetic risk (BRACA1 or BRACA2 genes), then first mammogram should be at age 35 years. Annual mammograms thereafter.
- Performance of routine gynecologic examinations for women with developmental disabilities may require preparation of both patient and office staff.

**Here are some suggestions**

**Preparation of the patient:**

1. Explain ahead of time
2. Role play
3. Define desired behavior
4. Rewards and reinforcers for participation
5. A tour visit of the office and examination room
6. A familiar person to accompany the patient.

**Preparation of the office staff:**

1. Schedule on uncrowded days
2. Plan for a short waiting time
3. Schedule a series of appointments
4. Provide staff for continuity
5. Explain procedure calmly and in a soft voice
6. Know that the procedure may take longer
7. If autistic, avoid restraints
8. Safety is a priority.
9. Consider specifics of the disability
10. Be flexible
11. Consider use of sedation

**Other considerations:**

- Use a narrow speculum such as a Pederson for virginal patients
- May use a Q-tip "blindly" to sample the os
- Consider use of pelvic ultra-sound if you cannot do a bimanual examination.
- Rarely a patient will require general anesthesia.

**Remember these words:**

PATIENCE, SENSITIVITY, FLEXIBILITY, CREATIVITY, DIGNITY, & RESPECT