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Aging with Developmental Disabilities: Women's Health Issues

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People with mental retardation and other developmental disabilities are living longer, and good health plays a vital role in their quality of life as they age. Women generally live longer than men, so a larger number of the growing population of older people with developmental disabilities will be women. More research is needed to understand all the specific health issues of aging women with developmental disabilities and the ways to support a healthier life-style. However, it is important that older women with developmental disabilities receive the health-related information that is presently available in order to promote well-being and prevent health problems.

What is considered "normal aging" for women with developmental disabilities?

In the general population, women now live to around age 79 and men usually live to around age 73. A recent study found that among people with developmental disabilities age 40 and older without Down syndrome, the average age of death was 67 for women and 63 for men. For people age 40 and older with Down syndrome, the average age of death was 57 for women and 54 for men.

While women normally live longer, life expectancy can be higher or lower depending on a person's risk for developing certain diseases or other health problems. Some women with disabilities may experience unique changes in addition to or apart from typical aging processes. For example, many older women with a seizure disorder or cerebral palsy may be at greater risk for certain health problems due to long-term use of specific medications or conditions related to limited physical activity or mobility. Women with Down syndrome are likely to experience sensory, adaptive or cognitive losses earlier than most other women in general. Diet, exercise, other life-style factors, and access to quality health services also can affect a woman's health at any age.

What affect does menopause have on women with developmental disabilities?

Menopause is unique for every woman, including women with developmental disabilities. Menopause is typically thought of as the time when women stop menstruating. A woman is considered to have reached menopause if she has not had a menstrual period in one year. Menopause varies considerably from woman to woman, but it usually occurs around age 50-52.

The transition to menopause is a process that begins as a woman's body produces

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less and less estrogen and eventually menstrual periods stop permanently. Near the time of menopause, periods become less frequent and bleeding decreases. Since this natural drop in estrogen may be inconsistent, women who are in their mid to late forties should keep a calendar of their menstruation to help note any irregularities in their periods.

For most women, reaching menopause is a gradual transition. However, some women may experience menopause abruptly through surgical removal of both ovaries, radiation treatment, or by taking certain medications. Some women barely notice any changes related to menopause. Others may experience hot flashes, sweating, insomnia, heart palpitations, itchy skin, backaches, joint pain, headaches, bloating, weight gain, thinning hair and the growth of facial hair. Depression or other mental health changes may be associated with menopause for some women. However, the above changes may also have other causes not related to menopause, so a blood test for hormone levels may be necessary to determine if these changes are due to menopause

Diet, exercise, and additional rest can eliminate or relieve many of the unpleasant physical and psychological complaints associated with menopause. Practical tips like dressing in layers and in lightweight clothes help with periodic hot flashes. Decreasing caffeine and alcohol intake may also help. Hormone replacement therapy is sometimes recommended.

There is little research in the area of menopause and older women with developmental disabilities. However, several studies suggest that women with Down syndrome and women with epilepsy may reach menopause at an earlier age than women in the general population. For some women, seizure patterns change, for better or worse,

around the time of menopause. It is unclear if this is from the effects of hormones or changes in anti-seizure drug levels.

Women with developmental disabilities typically have not received information about the nature of menstrual periods and menopause. Therefore, it is important to inform women about menopause and to arrange for periodic evaluations by a health care professional with expertise in women's health.

What is hormone replacement therapy?

Hormone replacement therapy (HRT) is a treatment to supplement or replace the hormones that the body no longer produces during menopause. HRT involves taking one or more hormone medication supplements as prescribed by a physician. Supplements are available as pills, as a patch applied to the skin, or as a gel.

The potential benefits of HRT have to be weighed against the potential risks of harmful side effects. Potential benefits include a decreased risk for heart disease, relief from hot flashes and/or mood swings and reduction in osteoporosis (thinning of the bones). In addition, there is evidence that HRT may reduce the risk of developing Alzheimer's disease. However, the use of HRT may have a relationship to the progression of breast and uterine cancers for women who are at risk, and women with decreased mobility may be at a greater risk for developing blood clots. HRT may also negatively interact with medications such as insulin and blood thinners. It is important to discuss the benefits and risks of HRT with a health care provider who has expertise in this area. This discussion should consider a woman's unique family and medical history, including her use of other medications.

What is osteoporosis and how does it affect women with developmental disabilities?

Osteoporosis is a disease in which bones become fragile and are more likely to break. Unfortunately, many older women become aware that they have osteoporosis only after they break or fracture a bone.

Estrogen helps maintain bone density. The natural drop in estrogen because of menopause increases a woman's risk for osteoporosis. Other risk factors include: advanced age, family history of osteoporosis, Caucasian or Asian ethnicity, very thin or small stature, physical inactivity, a condition which limits movement, early menopause, a diet low in calcium or vitamin D, high alcohol and/or coffee intake, over-dieting, excessive weight loss, and smoking. The more risk factors a woman has, the higher her chances are for getting osteoporosis. Women who have several of these risk factors should have a special bone x-ray (e.g., DEXA) to determine if osteoporosis is present and the rate of bone loss.

Women with developmental disabilities may be at greater risk for osteoporosis and related bone fractures due to amenorrhea (the absence of periods), earlier menopause, the use of certain medications (anticonvulsants, excessive thyroid hormones, steroids), and because they are more likely to be inactive or experience falls. Recent studies suggest that people with certain conditions like Prader-Willi or Klinefelter's syndromes may be at increased risk for osteoporosis. Women with cerebral palsy may be at greater risk for developing a number of other bone, muscle, and joint-related diseases as they age, such as scoliosis (abnormal curvature of the spine) and spinal stenosis (neurologic problems associated with narrowing of the spinal canal).

What are some ways to prevent osteoporosis?

Because bone loss takes place over time, women need to have an adequate intake of calcium and vitamins throughout their lives. Dairy products, dark green leafy vegetables, broccoli, salmon, cheese, sardines and tofu are high in calcium. Some foods, like orange juice and cereals, may have calcium added. Try to select three or more of these foods every day. A nutritionist or health care provider can recommend daily dietary guidelines and other sources of calcium and vitamin D. These nutrients can also be obtained by taking supplements. In addition, women should avoid caffeine and excessive alcohol because these interfere with the body's ability to naturally absorb calcium.

Other factors that may help prevent osteoporosis include:

Exercise: Weightlifting and other weight-bearing activities can help improve bone density and maintain general health as well. Many exercises can be modified for women who have physical limitations or use wheelchairs. Regardless of which activities are performed, most women should begin exercising regularly early in life and continue as they get older. However, women who begin exercising later in life can also benefit.

Weight: Obesity is a common problem for older women with developmental disabilities, especially for women with Down syndrome. Environmental and genetic influences on body size and shape can make weight control difficult for some women, and eating problems can also be related to psychosocial factors such as depression and anxiety. However, an overweight individual who exercise regularly may actually be more physically fit and at lower risk for osteoporosis than her thinner, less physically fit peers.

Tobacco: Cigarette smoking is one of the leading preventable causes of major health problems in older adults. It contributes to osteoporosis because it decreases the body's ability to process calcium. Smokers have double the risk of hip fractures than nonsmokers. Women who smoke should be encouraged to quit, including those who have smoked for many years. Although trying to quit smoking may be difficult, treatments such as behavioral strategies and medication (nicotine) in the form of gum, skin patches and nasal sprays have helped some people.

Medications: Hormone Replacement Therapy (HRT) may be one of the most beneficial means of preventing osteoporosis for some, but not all, women due to possible health-related risks mentioned above (e.g. cancer, blood clots). Most HRT information is based on studies of women without disabilities. More research is needed to determine whether HRT poses any additional benefits or harmful risks for women with developmental disabilities.

Is heart disease a concern for women with developmental disabilities?

Heart disease accounts for half of all deaths of women over age 50. Preliminary research suggests that it may be a leading cause of death for women with developmental disabilities as well. Generally, women are not diagnosed as early as men are, so their heart condition is not treated until it is much more serious. Major risk factors for developing heart disease include family history, hypertension, diabetes, lack of cardiovascular fitness, and smoking. Menopause also can increase the cholesterol levels in a woman's blood, which can lead to a greater risk of heart disease or stroke. Warning signs of a heart attack include shortness of breath; pain or tightness in the chest, arm or jaw; dizziness; fainting; and, lack of

energy. Women may be able to lower their risk for heart disease by reducing high cholesterol, controlling hypertension and diabetes and following a healthy life-style.

Are women with developmental disabilities at risk for cancer?

Like heart disease, cancer is one of the leading causes of death for women, including women with developmental disabilities. Older women should receive regular screenings and examinations for early detection of breast, ovarian and uterine cancer, especially if they are sexually active or postmenopausal. Women with developmental disabilities often do not receive these services. Frequently, families are unaware of this need and many health care professionals are inexperienced and/or untrained in working with women who have disabilities. In addition, many clinics and offices lack adaptive equipment to accommodate women with physical disabilities.

Family history, age, never having children or a first pregnancy after age 30, and the long-term use (10 years or more) of estrogen all increase the risk of developing breast cancer. A clinical breast exam by a health care professional should be done at least once every year. If possible, women should be taught to examine their own breasts on a monthly basis. Mammography, which is an x-ray examination of the breasts, should be done regularly, although there is some disagreement in the medical community on how often it is necessary. Women ages 40-50 should discuss with their health care provider when to begin getting mammograms, and all women should begin having regular mammograms by age 50.

If a lump or mass is detected during a screening, the doctor should follow-up with further tests such as diagnostic mammograms or breast ultrasound,

which is also known as a sonogram. Ultrasound uses sound waves to create an image on a computer screen of the lump/mass. Unlike the mammogram, no radiation exposure occurs during this test. Although some new drugs show potential benefits in preventing and treating breast cancer, their use should be discussed with a health care professional.

Most women should have a pelvic exam and a Pap smear, which is a screening test for cancer of the cervix (opening to the uterus). These should be done once every 3-5 years to rule out health problems. If a woman is on HRT or if a previous Pap test detected abnormal results, the doctor should conduct these exams more frequently. It is important for postmenopausal women to report spotting, staining or bleeding to their health care provider because these may be warning signs of cancer or other serious conditions. A woman with developmental disabilities may end up ignoring these warning signs because she has never been told what to expect with menopause.

Is thyroid disease a concern for women with developmental disabilities?

The thyroid is a gland that helps control how fast or slow your body functions, such as the rate at which your body burns calories. Sometimes health conditions are caused by an overactive thyroid (hyperthyroidism) when there is too much thyroid hormone or by an underactive thyroid (hypothyroidism) when there is too little thyroid hormone.

In the general population, the risk of thyroid disease is higher for women, older adults, and people with a family history of this condition. There is also a higher rate of thyroid disease among people with Down syndrome. Thyroid disease is often overlooked because many of the symptoms, such as fatigue, constipation, dry skin,

and poor concentration, are frequently associated with other health problems. Health care professional may recommend regular thyroid screenings for older women, especially those with Down syndrome, so they can benefit from early detection and treatment.

How is urinary incontinence related to aging?

Around the time of menopause, some women may have difficulty in controlling their urination, leading to urinary 'accidents'. This is known as urinary incontinence. Women with a prior history of urinary incontinence may experience increased difficulty in controlling their bladder. For older women with cerebral palsy or other neuromuscular conditions, urinary incontinence may be related to both aging and their physical disability. As women age, changes in the urinary tract can also increase the risk of urinary tract infections (UTI). Frequent symptoms of a UTI include an increased need to urinate and a burning sensation or discomfort during urination. If left untreated, this can contribute to urinary incontinence and lead to more serious health problems.

More frequent urination and making sure toilet facilities are nearby and accessible can reduce urinary incontinence problems. Exercises can also strengthen the muscles that aid in urination and support the bladder. The Kegel exercise, for example, involves stopping and starting the flow of urine to locate and strengthen the appropriate muscle. This exercise can then be continued when not urinating to maintain and further improve muscle tone. Incontinence may often go unreported because the person is embarrassed or has communication difficulties. An accurate diagnosis is usually necessary to help treat any incontinence.

What other preventive health care services do older women with developmental disabilities need?

The onset and severity of health problems can be better treated if caught early. Periodic health examinations are recommended for all women, including women with developmental disabilities. These should include a thorough physical exam and vision, hearing and dental exams. Women age 65 and older should also be tested for diabetes, colon/rectal cancer, hypertension, total cholesterol levels and iron deficiency. Additionally, access to mental health services is important because women with disabilities may be at risk for mental health problems such as depression and suicide, which often go undetected.

What health-related supports and accommodations should women with developmental disabilities receive?

Older women with developmental disabilities are generally uninformed about many of the changes that their bodies are, or will be, going through. Family, staff and close friends can play an important role in the health and well-being of women with developmental disabilities by:

- Watching for behavioral changes that may indicate an underlying health problem, especially for women who have communication difficulties.
- Ensuring access to appropriate health information and to health professionals who are experienced in diagnosing and treating age-related health problems for women with disabilities.
- Ensuring that health professionals have accessible examination rooms and the proper equipment to examine women with disabilities appropriately.

- Providing the necessary supports to address health concerns, including alleviating their fears and helping them feel comfortable with the health care professional and the examinations/procedures.
- Ensuring that health information is available, understandable and explained in a way that is respectful.

For more information and assistance on disability and women's health issues:

Video: Let's talk about health - What every woman should know: The GYN exam. by The Arc of New Jersey. (VHS videotape, 1 audiotape and 2 booklets titled, *Let's talk about health - What every woman should know: The GYN exam.* 23 pgs.). 1995. \$28. Available from The Arc of the United States, P.O.B. 1047, Arlington, TX 76004.

Let's talk about health - What every woman should know: The GYN exam. by The Arc of New Jersey. 23 pgs. 1995. (same booklet as above). 1-9 copies, \$4 ea.; 10-29 copies, \$3.50 ea.; over 29 copies, \$3 ea. Available from The Arc of the United States, P.O.B. 1047, Arlington, TX 76004.

Resourceful Woman: Women with Disabilities Striving Toward Health and Self-determination. The Health Resources Center for Women with Disabilities. Rehabilitation Institute of Chicago.

Table Manners: A Guide to the Pelvic Examination for Disabled Women and Health Care Providers (1991). Planned Parenthood Alameda/San Francisco, CA

ADA Health Care Facility Access Project
The National Rehabilitation Hospital
Washington D.C., 20010.

Internet-Based Resources:

Research Homepage for Older Women with Disabilities
www.uic.edu/~lisab/homepage.htm

Electronic Discussion Group (Listserv) on Women's Health and Aging with Developmental Disabilities. *To subscribe to the forum, send email message to Listserv@listserv.uic.edu, and type:*
Subscribe WomHlthAging-DD <YourFirstName>
<YourLastName>

Disabled Women's Sexual and Reproductive Health Resource Packet, International Leadership Forum for Women with Disabilities
www.prodworks.com/ilf/sr_info.htm

Center for Research on Women with Disabilities (CROWD)
www.bcm.tmc.edu/crowd/baylor2.html

AHCPR Women's Health Highlights. Fact Sheet. AHCPR Pub. No. 98-P004, May 1998. Agency for Health Care Policy and Research, Rockville, MD.
www.ahcpr.gov/research/womenh1.htm

Our Bodies, Ourselves: For The New Century. Boston Women's Health Book Collective. New York: Simon and Schuster, 1998. A book by and for women about health and sexuality.
www.ourbodiesourselves.org

Breast Health Access for Women with Disabilities
www.salick.com/resource/features/abbreast

National Osteoporosis Foundation
www.nof.org

Epilepsy Foundation of America
www.efa.org/what/wei/index.html

American Heart Association
www.amhrt.org

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Important Information

1. Get a yearly physical that includes a clinical breast exam and pelvic exam. Ask your health care provider about immunizations such as flu, pneumococcal and Tetanus-diphtheria shots.
2. Have a baseline/regular mammogram and Pap test as recommended by your health care provider.
3. Get regular dental check-ups and complete eye exams and hearing tests at least every three years. Have your cholesterol levels and blood pressure checked regularly.
4. Keep a menstrual calendar to keep track of any changes.
5. Quit smoking and avoid drinking excessive amounts of alcohol.
6. Try to get seven to eight hours of sleep each night.
7. Exercise daily. Include a variety of exercises such as strength training, stretching, walking, swimming, dancing, bicycling or exercising to a video.
8. Eat a healthy diet. Include a variety of foods from the major food groups (fruits/vegetables, breads/cereals, dairy/proteins, and a little fat), but try not to overeat. Don't starve yourself on crash diets for weight loss—they don't work.
9. Increase your calcium intake either through dairy products, calcium fortified foods, or supplements.
10. Socialize with friends/family and participate in a variety of recreational activities. Spend time with your pets, too. It is good for you and they will love you for it.
11. If you are upset, let someone know how you feel and assist you in finding ways to feel better.
12. Laugh a lot! It's good for your health!

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