

summary

- People with Down syndrome experience the same range of sexual feelings as the general population.
- Teenagers with Down syndrome undergo the same changes at puberty as all adolescents, though these changes may be slightly delayed for boys with Down syndrome.
- While the overall fertility of men with Down syndrome may be significantly reduced, it is still advisable that couples use contraception whenever pregnancy prevention is desired.
- At least 50 percent of women with Down syndrome are fertile. Healthy females can use contraception without added medical risk.
- Education is an appropriate and highly desirable component in developing positive sexual awareness for the individuals with Down syndrome.

For additional information and a resource list on sexuality and Down syndrome, visit our Web site at www.ndss.org or contact the NDSS information and referral center at 800-221-4602 or info@ndss.org.

NDSS thanks Dr. William Schwab for the preparation of this brochure.

about ndss

Our Mission:

The National Down Syndrome Society works through education, research and advocacy, to ensure that all people with Down syndrome have the opportunity to achieve their full potential.

Our Constituents:

Today, there are 350,000 people in the United States living with Down syndrome. Each of these individuals touches the lives of family members, educators, employers, health care professionals, peers and others. This network of people who are affected by Down syndrome numbers in the millions.

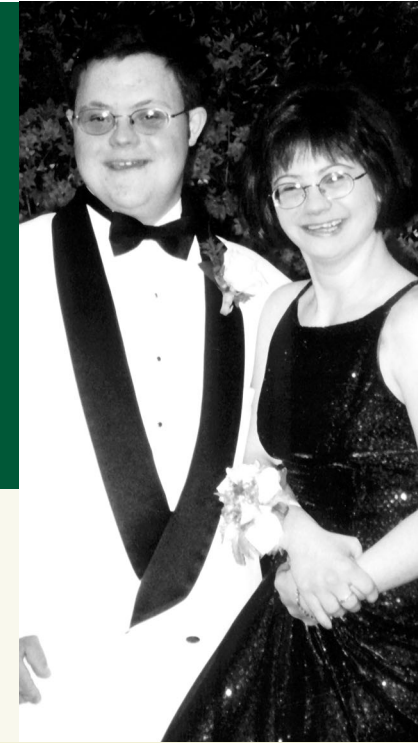
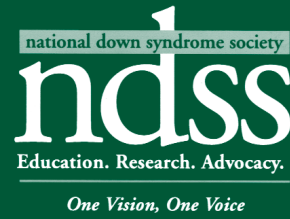
Our Programs:

Education. Through our model programs, Web site, Information and Referral Center and more, NDSS provides targeted, in-depth information that meets the diverse needs of our constituents. **Research.** The Society hosts international research conferences and funds research both independently and through a partnership with the NIH. NDSS is the largest private funder of Down syndrome research in the U.S. **Advocacy.** In cooperation with our more than 135 affiliate groups, NDSS has influenced important local and federal legislation, established October as National Down Syndrome Awareness Month, organizes the Buddy Walk and much more.



666 Broadway, New York, NY 10012
Telephone: (800) 221-4602
Fax: (212) 979-2873
Web Site: www.ndss.org
E-Mail: info@ndss.org

Copyright 2002
National Down Syndrome Society
All Rights Reserved



NATIONAL DOWN SYNDROME SOCIETY

sexuality in down syndrome

CLINICAL
INFORMATION SERIES

SEXUALITY AND DOWN SYNDROME

—by William Schwab, M.D., Associate Professor,
Department of Family Medicine and Practice
University of Wisconsin

Human sexuality encompasses an individual's self-esteem, interpersonal relationships and social experiences relating to dating, marriage and the physical aspects of sex. Sex education, appropriate for the developmental level and intellectual attainment of individuals with Down syndrome, helps in engendering healthy sexuality, preventing unwanted pregnancy and diseases and in alleviating other problems related to sexual function.

QUESTION: Do individuals with Down syndrome have sexual feelings?

ANSWER: In the past, sexuality was not considered an issue for young people with Down syndrome because of the inaccurate belief that mental retardation was equivalent to permanent childhood. In fact, all people with Down syndrome do have intimacy needs and sexual feelings, and it is important that these be recognized and planned for in education, housing and other programs and settings.

QUESTION: Do children with Down syndrome develop physically the same way as their peers in the general population?

ANSWER: Children with Down syndrome experience the same sequence of physical and hormonal changes associated with puberty as other children their age.

QUESTION: Do children with Down syndrome experience the emotional upheavals characteristic of adolescence?

ANSWER: The emotional changes characteristic of adolescence are also present in children with Down syndrome, and may be intensified by social factors. Any adolescent who lives in the community, attends school and is exposed to media inevitably develops an awareness of sexuality. Teenagers and young adults with Down syndrome often express interest in dating, marriage and parenthood. They can be expected to experience typical adolescent changes in mood and outlook.

QUESTION: What kind of sex education is appropriate for individuals with Down syndrome?

ANSWER: To be effective, education must be individualized and understandable, focusing not only on the physical reproductive aspects, but also positioning sexuality within the context of all interpersonal relationships. An ideal curriculum

will ensure that the individual's understanding of relationships, sexual intercourse and parenting is factual, realistic and socially acceptable.

QUESTION: How can healthy sexuality be encouraged for individuals with Down syndrome?

ANSWER: Creating an environment conducive to healthy sexual expression must be considered in designing educational, vocational, recreational and residential programs. Positive sexual awareness can only develop through self-esteem, understanding of social relationships and personal interaction/communication skills. All these factors influence how intimacy needs are met.

QUESTION: Do women with Down syndrome have any special needs or concerns in regard to birth control?

ANSWER: Approximately 50 percent of women with Down syndrome are fertile and may use any method of contraception without added medical risk. The method chosen will depend on personal preference, ability to use the contraceptive effectively and possible side effects. Surgical sterilization may also be performed without added risk for women with Down syndrome who are in stable medical condition; however, availability of this procedure to women who are developmentally disabled may be controlled by state law. The individual with Down syndrome should be involved as much as possible in decision-making should this option be considered.

QUESTION: Are there any special needs for individuals with Down syndrome in regard to disease prevention?

ANSWER: Men and women with Down syndrome have the same susceptibility to sexually transmitted diseases as the rest of the population. Use of condoms during sexual intercourse is the best known form of protection

against AIDS, herpes and other sexually transmitted diseases. Sexual education should include information on sexually transmitted diseases and how to prevent them.

QUESTION: How can a person with Down syndrome be protected against sexual abuse?

ANSWER: It is highly recommended that age-appropriate education in protective behaviors begin in childhood and be reinforced throughout the life of the person with Down syndrome. Individuals with Down syndrome must be taught the boundaries of normal physical interactions in the social sphere, as well as the self-assertion skills to enlist help if necessary.

QUESTION: Do girls with Down syndrome have normal menstrual periods?

ANSWER: Menstruation for girls with Down syndrome is no different than for their peers in the general population. On the average, they begin menstruating at age 12½, but may begin as early as age 10 or as late as age 14. Most girls with Down syndrome have regular cycles with the same minor irregularities typical of their peer group.

Alterations in a previously regular cycle may be due to the normal process of aging, or may be a sign of emerging hyperthyroidism. Ongoing irregularity of menstrual cycle warrants medical examination.

QUESTION: If a woman with Down syndrome becomes pregnant, will the baby have Down syndrome?

ANSWER: At least half of all women with Down syndrome do ovulate and are fertile. Between 35 and 50 percent of children born to mothers with Down syndrome will have trisomy 21 or other developmental disabilities.

QUESTION: When is the onset of menopause for women with Down syndrome?

ANSWER: Menopause may occur at a wide range of ages. Typically it takes place after age 40.

QUESTION: Are males with Down syndrome fertile?

ANSWER: Scientific information about the fertility of men with Down syndrome is limited. There have been at least two documented cases where the paternity of a man with Down syndrome was confirmed. It is likely that additional cases will be recognized—especially as more men have the opportunity to live in the community and develop intimate relationships. It is not known if the offspring of men with Down syndrome are more likely to have Down syndrome or other anomalies. It does seem clear that, in general, men with Down syndrome have a significantly lower overall fertility rate than that of other men of comparable ages. An individual's status can be partially assessed by having a semen analysis done, but this may not be definitive. If a couple desires pregnancy prevention, contraception should always be used.

QUESTION: Do boys with Down syndrome mature later than their peer group in the general population?

ANSWER: The onset of puberty in boys may be slightly delayed, but this is not a major factor. Genital anatomy is comparable to that of boys who do not have Down syndrome.