

Sexual and Reproductive Health for Girls and Women

Like people in the general population, those with 22q differences are interested in relationships and sex. Some would also like to have their own babies some day. Sexual and reproductive health may not be a comfortable topic, and it may be forgotten in the midst of other health issues. However, it is important to provide **positive and health-based support** and balance sexual wants, needs, and concerns. This sheet gives an overview and talks about contraception, sexually transmitted infections, and cancer prevention.

Sex and 22q Differences

- People with 22q differences have sexual desires and rights, just like people in the general population;
- However, many people with 22q differences have **deficits in planning, judgement, and functioning**;
- Many **lack knowledge about safe sex and consent**; often leading to **negative health outcomes**;
- For info on consent, see [Social Life and Personal Safety](#).

Preventing Unwanted Pregnancies

- People with 22q differences may need to be reminded that **having sex can lead to having babies**;
- **Birth control** (contraception) helps prevent pregnancies:
 - There are **many methods, each with pros and cons**;
 - Hormonal methods like [pills](#), [patches](#), [rings](#), [injections](#), [IUDs](#), and [implants](#) are effective at preventing pregnancies but they do not prevent sexually transmitted infections (STIs; see next page);
 - IUDs or implants are easier for some people since they don't have to remember to use them;
 - [Condoms](#) can help prevent both pregnancies and STIs, but only if they are used correctly;
 - Tracking ovulation or pulling out before ejaculation are not effective at preventing pregnancies or STIs.

It is recommended that healthcare providers explain birth control options to all patients with 22q differences.

Issues Related to Pregnancies

- Women who are thinking about having babies should:
 - See health care practitioner before pregnancy to make sure medications are safe to use in pregnancy.
 - Take folate supplements;
 - Get health checks throughout their pregnancies.
- Women with 22q11.2DS who were born with heart disease and plan to have babies need special care.
- Fetuses with 22q11.2DS have a higher risk of birth defects, abnormal growth, having too much fluid in the womb, and stillbirth.
 - It is best for them to be born at special hospitals where they can get expert care.

Sexual activities & 22q11.2DS

In a [study](#) of 67 Canadians (39 were female) between 17 to 63 years old with 22q11.2 deletion syndrome:

- Heterosexual – 82%
- Sexually active – 66%
 - First sex: 12 to 31 years old
 - 24/33 (73%) have had 2 or more partners
- Unwanted sex – 36%
- Any high-risk behavior – 82%
- Sexually transmitted infection – 18%
- Drugs and/or alcohol before sex – 25%
- Unprotected sex (no condoms) – 64%
- Pregnancies – 13 females had pregnancies. 11 (85%) had 1 or more unplanned ones; 21/27 (78%) pregnancies in the 11 females were unplanned.

22q11.2 Differences and Fertility

The chances of getting pregnant (or getting someone pregnant) is lower for people with 22q11.2 deletion syndrome who are:

- Men;
- Born with severe heart disease;
- Affected by severe intellectual disability;
- Affected by psychotic illness (cannot tell what is real and what is not).

Not a lot is known about the fertility of people with 22q11.2 duplications.

Genetic Counselling

Both men and women with a 22q11.2 deletion or duplication have a 50% chance of passing it on in each pregnancy. It is recommended that **people with 22q difference receive genetic counselling before trying to have babies**.

[Prenatal Screening and Diagnostic Considerations for 22q11.2 Microdeletions](#) provides recommendations for pregnancies involving 22q11.2 deletions in the parents and/or the baby.

Sexual and Reproductive Health for Girls and Women (continued)

Sexually Transmitted Infections (STIs)

Also called Sexually Transmitted Diseases (STDs)

- STIs happen when the body gets infected by bacteria, viruses, or parasites during sexual activities involving the mouth, anus, vagina, or penis;
- The most common types of STIs include:
 - [Chlamydia](#);
 - [Genital herpes](#);
 - [Genital warts](#);
 - [Gonorrhea](#) (clap);
 - [Hepatitis B](#);
 - [HIV/AIDS](#);
 - [Syphilis](#);
 - [Human papillomavirus](#) (HPV);
 - [Trichomoniasis](#) (trick);
 - [Pubic lice](#) (crabs);
- **Anyone who is sexually active can get STIs.** People can also get STIs from shared needles (e.g. tattoos, drugs) and piercings (ear rings);
- Some STIs have symptoms like a burning feeling, itchiness, warts, or mucus or blood from your private area; some STIs have no symptoms;
- People with STI can pass it onto their sex partners without knowing;
- Test for STIs yearly, as untreated STIs can lead to severe health problems;
- To reduce the risk of getting STIs:
 - Use condoms properly and routinely when having sex;
 - **Get the HPV vaccine**, as HPV can infect areas where condoms do not cover.

Cancer Prevention

- Some high-risk HPV infections can lead to cancers in the throat, head and neck, penis, anus, vagina, vulvar, and cervix.
- **Most cervical cancers are caused by high-risk HPV infections.**
- Check with your healthcare provider about [cervical cancer screening](#).
- **To reduce the risk of cervical cancer:**
 - **Get the HPV vaccine**, ideally before becoming sexually active, but any time after 9 years old is fine;
 - Limit the number of sex partners;
 - Do not smoke.

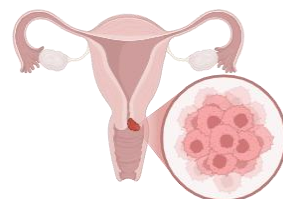
References / Resources

- Updated clinical practice recommendations for managing [\[children | adults\]](#) with 22q11.2 deletion syndrome – 2023
- [Prenatal Screening and Diagnostic Considerations for 22q11.2 Microdeletions](#) – 2023
- [Reproductive Outcomes in Adults with 22q11.2 Deletion Syndrome](#) – 2022
- [Sexual knowledge and behaviour in 22q11.2 deletion syndrome, a complex care condition](#) – 2021
- [Contraception](#) (pdf) – Society of Obstetricians and Gynaecologists of Canada
- [Sexually transmitted infections \(STIs\) | Cervical Cancer](#) – Alberta Health Services

- [Birth control for teens](#) – Canadian Paediatric Society
- [Birth Control | Sexually Transmitted Infections | Masturbation | Cervical Cancer Screening | HPV Vaccine](#) – Cleveland Clinic
- [Teaching Sexual Health](#) (for Teachers and Parents) – Alberta Health Services / Primary Care Alberta
- [HPV vaccine: Who needs it, how it works](#) – Mayo Clinic
- [HPV](#) (video) – Canadian Cancer Society
- [Cervical cancer](#) graphic – Biorender

Masturbation

- Masturbation means stimulating a person's private areas to get sexually aroused. It is common and natural;
- It can be done on oneself or on a partner, and there is no risk of pregnancy;
- Masturbation has many physical and health benefits, e.g. It reduces stress, tension, and pain;
- Myths and taboos about masturbation exist, but there is nothing medically wrong about it;
- However, if masturbation becomes compulsive or affects your relationships, discuss the problem with your medical practitioner.



Cervical cancer is an abnormally-growing mass of cells in the cervix. The cervix is the opening to the uterus (the womb) in biological females.