

Sexual Health



Romantic relationships, sexual activity and pregnancy are important parts of adult life for people with 22q11.2 deletion syndrome (22q).

Did you know...

- Sexual health includes your physical, emotional, mental and social well-being.
- People with 22q are able to have children.
- People with 22q have a 50% (1 in every 2 pregnancies) chance of having a child with 22q.
- People with intellectual disabilities are at greater risk to be sexually abused.

Tips for young adults

- You have the right to learn about all parts of your sexual health. Don't be afraid to ask your doctor, nurse or social worker questions.
- If you are going to have sex with someone, learn about birth control (contraceptives) – choose one that feels right for you, whether you are a man or a woman.
- If you are thinking about having children, it is a good idea to ask to see a genetic counsellor to talk about the chance of having a child with 22q and your/your partner's care during a pregnancy.
- If you meet someone online, take someone with you if you go to meet them in person.
- It is never okay for someone to pressure you into sex or to touch you in a way that makes you feel uncomfortable – if this happens, talk to someone you trust.

Tips for caregivers

- Sexual health education must suit your young adult's level of understanding. Be concrete and use visuals. You may need to cover the same topic several times or explain it in different ways.
- Educate about inappropriate sexual behaviours that could cause harm (like sexting), but do not punish.
- Be aware of signs of sexual vulnerability or abuse (e.g. physical – bruises, difficulty walking or sitting, sexually transmitted infections; behavioural/psychological – changes in socialization patterns, mood).
- Guide your young adult to appropriate supports and resources. If you don't know, ask for help from members of your young adult's health-care team.

Sexual health and reproductive issues checklist

Have you had any of the following?

- Unwanted sexual activity or sexual abuse.
- Wondered about what kind of birth control would be right for you.
- Felt confused about your feelings for someone of the same or someone of the opposite sex.
- Want to have a child and want to know if there are any special issues for you.
- Worried that you might have a sexually transmitted infection.
- Been upset by someone touching you, sending you a picture or asking for sex.

If you answered yes to any of the above, you may want to talk to your doctor, a member of your health-care team, or someone you feel comfortable with.

Please contact us if you have any questions

22q Deletion Syndrome Clinic

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This fact sheet was produced in collaboration with the **Good 2 Go Transition Program** at The Hospital for Sick Children. www.sickkids.ca/good2go/

Note: 22q11.2 deletion syndrome ("22q" or "22q11.2DS") has also been known as DiGeorge syndrome, velocardiofacial syndrome, and many other names. For more information, please visit www.22q.org/awareness-events/awareness/same-name-campaign/.