

Being prepared for a medical emergency

People with 22q11.2 deletion syndrome (22q or 22q11.2DS) often have health issues. These can include problems regulating blood calcium levels, heart rhythm abnormalities, and seizures. In some cases, these issues can lead to a medical emergency.



Know when to call

911

Tips for young adults

- Know the name of your medical condition: “22q11.2 deletion syndrome (22q or 22q11.2DS)”
- Carry either a **MyHealth Passport** (from SickKids) or a **Medical Information Card** (from Dalglish Clinic) at all times. These cards list your conditions and medications that emergency responders will need to be aware of.
- Know the names and doses (amounts) of any medications you take
- It is unsafe to drink alcohol if you take medication – this can cause a bad reaction or even a medical emergency. However, don’t stop taking your medications. Talk with your doctor if you have more questions about alcohol and medication interactions.
- Make sure you and your friends and family have a copy of your list of emergency contact numbers:

Name	Phone number(s)

Tips for caregivers

- Create a “MyHealth Passport” (<https://www.sickkids.ca/myhealthpassport/>) or ask the Dalglish Clinic to create a Medical Information Card for your young adults.
- Prepare a list of emergency phone numbers for your young adults.
- Teach your young adults when and when not to call 911
- Educate your young adults about their health conditions
- Consider getting your young adults a MedicAlert® bracelet to alert emergency response personnel to specific medical risks / conditions. Check with your young adults’ doctors.

What to do when calling 911

- (1) Stay calm. Call from a safe location.
- (2) Wait for your call to be connected. Do not hang up.
- (3) The dispatcher will ask "Do you need police, fire, or ambulance?" Answer based on what you need. Speak clearly.
- (4) Then the dispatcher will ask you to provide:
 - The address where the emergency is
 - The closest major intersection
 - Sometimes, there are multiple streets with the same name in a city. When you give the closest intersection, the dispatcher can send emergency crews to the correct street. Even if you cannot tell the exact corner of the intersection, it's okay. Give as much information as you can.
 - Your phone number
- (5) Answer the dispatcher's questions. If you don't know an answer, it's ok to say "I don't know."
- (6) Follow the dispatcher's instructions. Don't hang up until he/she asks you to do so.

Please contact us if you have any questions

22q Deletion Syndrome Clinic

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www.sickkids.ca/CGenetics/What-we-do/22q-deletion-syndrome-clinic/

The Dalglish Family 22q Clinic

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SICK CHILDREN



The Dalglish Family
22q Clinic

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/.