

RESOURCES

AboutKidsHealth - SickKids

AboutKidsHealth is a health education website for children, youth and their caregivers developed by experts at SickKids. Check out the “Heart Learning Hub” to learn more about pediatric heart disease. The teens website has great resources designed to address adolescent health.

<https://www.aboutkidshealth.ca/>

<https://teens.aboutkidshealth.ca/>

Resource Navigation Centre – SickKids

The Resource Navigation Service is available to assist families in finding and utilizing resources available to them. This service also supports SickKids patients and parents who require community information and help to apply for resources that can address their healthcare-related costs, as well as other specific needs.

<https://www.sickkids.ca/en/patients-visitors/financial-legal-assistance/>

Exercise Medicine Program – SickKids

The Exercise Medicine Program, created within the SickKids Labatt Family Heart Centre, promotes physical activity by providing individualized exercise programs for our patients based on a comprehensive medical and functional evaluation. For a referral to the program, speak to your child’s cardiologist or cardiac nurse.

<https://www.sickkids.ca/en/care-services/clinical-departments/cardiology/>

Cardiac Kids

Cardiac Kids is a volunteer group established in 2000 to raise much-needed funds for Canadian children who are suffering from congenital heart disease. Initiatives supported by Cardiac Kids include the annual SickKids Labatt Family Heart Centre Family Conference and Sibling Day, Camp Oki, and the Cardiac Transition Program.

<https://www.cardiackids.ca/index.shtml>

I♥Change

This website is designed mainly for young people with congenital heart disease and was developed by healthcare professionals with expertise in transition and congenital heart disease. The aim of the website is to help people feel more ready to “transition” from pediatric to adult care.

www.iheartchange.org

Canada Food Guide – Government of Canada

Developed by the Canadian Office of Nutrition Policy and Promotion, Canada’s food guide helps you choose foods that: improve health, meet nutrient needs, and reduce risk of nutrition-related, chronic (long-term) diseases and conditions. Canada’s food guide uses the science of nutrition and health to help you make healthy food choices.

<https://food-guide.canada.ca/en/>

Healthy Living – Government of Canada

Visit this website to learn more about ways in which to stay healthy, including information physical activity, substance use, smoking/vaping, sexual health, pregnancy and mental health.

<https://www.canada.ca/en/services/health/healthy-living.html>

What’s Up Walk In – Mental Health T.O.

What’s Up Walk In provides free, virtual mental health counselling for children, youth, young adults and their families, and families with infants.

<https://www.whatsupwalkin.ca/>

Kids Help Phone

Kids Help Phone is a Canadian resource to support the mental health and well-being of young people. Contact Kids Help Phone for support with any including bullying and abuse, friends and family, emotional well-being and more. Kids Help Phone’s e-mental health services include phone and text support. Their one-to-one services are free, available in English and French and open 24/7.

<https://kidshelpphone.ca/>

Health Care Connect – Ontario Ministry of Health

Helps Ontarians find a family health-care provider (physicians, nurse practitioners)

www.health.gov.on.ca/en/ms/healthcareconnect/public

211 Ontario

A helpline that easily connects people to the social services, programs and community supports.

www.211ontario.ca

P4P Planning Network

Partners for Planning is a national non-profit organization that supports people with a developmental disability and their families to be proactive in planning for the future.

<http://www.planningnetwork.ca>

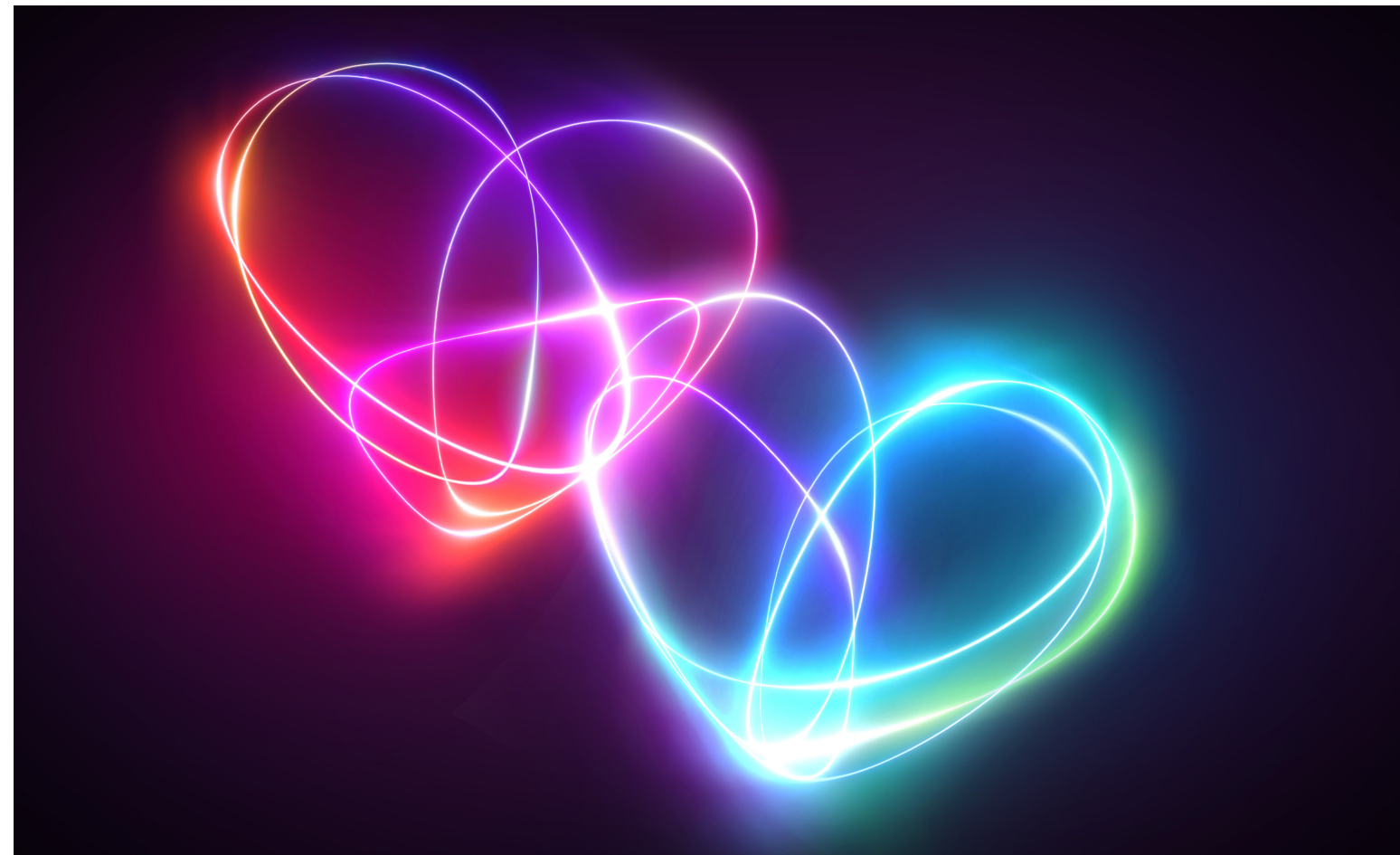
MedicAlert Foundation Canada

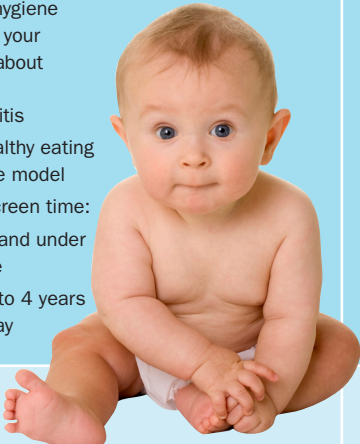




Register with MedicAlert to create a customizable medical ID bracelet. The MedicAlert Foundation supports Canadians with 24/7 notification of loved ones, and a special hotline for paramedics, police, and emergency responders to get access to a subscribers detailed medical profile.

<https://www.medicalert.ca/>



CARDIAC TRANSITION TIMELINE



	FOR PARENTS			FOR TEENS/YOUTH	
	Birth to 3 years old	4 to 7 years old	8 to 11 years old	12 to 15 years old	16 years old and up
Lifestyle/General	<ul style="list-style-type: none"> Be a part of your child's healthcare team If you are concerned about your child's feeding, speak to a dietician or occupational therapist Track and keep up-to-date with immunizations Take breaks to renew your energy Resources are available to help you cope with your child's diagnosis. Ask your healthcare team to learn more 	<ul style="list-style-type: none"> Teach your child that behaviour and choices have consequences and be consistent. This will help your child feel more secure Let your child play out hospital experiences with puppets or dolls Don't let your child's heart condition get in the way of life! Expect and encourage normal childhood experiences 	<ul style="list-style-type: none"> Recognize your child's increasing need for independence and responsibility at home Be aware of your child's activity on the internet. Create family rules around internet use, just as you would for other activities Talk to your child about the negative effects of smoking/vaping, drugs, alcohol, inactivity and a poor diet 	<ul style="list-style-type: none"> Ask questions, talk about your needs, and how you feel about your heart condition with your family and healthcare team Review internet safety rules with your family Speak with a trusted adult if you are being bullied in any way (either online or in-person) Practice budgeting and banking skills 	<ul style="list-style-type: none"> Know the differences between pediatric and adult health care systems Learn about confidentiality, informed consent and knowing your patient rights Think of yourself as a role model and consider being a mentor to younger children with a heart condition Review internet safety rules with your family Speak with a trusted adult if you are being bullied in any way (either online or in-person) Celebrate your "graduation" to adult care
Social/Physical	<ul style="list-style-type: none"> Encourage your child to play with others. This will help develop cognitive and motor skills Join community activities, such as play groups and parenting classes Set limits for your child to increase positive social behaviour 	<ul style="list-style-type: none"> Encourage an active lifestyle Encourage participation in school and community activities Introduce your child to a variety of activities, such as going to the library, playing sports or music Let your child become more independent Celebrate your child's achievements 	<ul style="list-style-type: none"> Encourage your child to form friendships with other children around the same age as your child Encourage your child to be physically active for 60 minutes a day. This can include activities such as biking, sports, dancing, and swimming Help your child recognize special talents and interests 	<ul style="list-style-type: none"> Be physically active. Aim for 60 minutes a day of vigorous exercise, for example swimming, biking, sports, or dancing Ask your cardiologist if you have any physical activity restrictions Join teams and clubs at school or get involved in activities outside of school, such as camps or community programs Hang out with friends Talk about dating with your parents, friends or someone else you trust 	<ul style="list-style-type: none"> Look for young adult support groups in the community (for example, The Canadian Congenital Heart Alliance) Continue to participate in activities at school and in your community If you are dating, decide when you are ready to talk about your health condition with your partner Keep physically active. Aim for 60 minutes a day of vigorous exercise, for example swimming, biking, sports, or dancing Discuss any changes to activity restrictions with your cardiologist
Self-care	<ul style="list-style-type: none"> Follow a daily routine with your child Teach your child everyday skills, such as hand-washing Practice good oral hygiene with your child. Ask your child's cardiologist about your child's risk of Infectious Endocarditis Show your child healthy eating by being a good role model Limit your child's screen time: <ul style="list-style-type: none"> Children aged 2 and under = no screen time Children aged 3 to 4 years old = 1 hour a day 	<ul style="list-style-type: none"> Encourage good oral hygiene – brushing teeth twice a day, flossing daily, and regular dental check-ups Ask your child's cardiologist if your child needs antibiotics before dental or other procedures (Endocarditis prophylaxis) Limit your child's screen time to a maximum of 2 hours a day Give your child household chores, such as cleaning or tidying Get your child involved in planning and preparing healthy meals Teach your child personal information, such as home address and phone number and how to call 911 Find out if your child needs a medical alert bracelet 	<ul style="list-style-type: none"> Encourage good brushing and flossing technique. Ensure your child receives antibiotics before dental or other procedures (endocarditis prophylaxis), if required Promote healthy eating with meal planning and cooking using Canada's Food Guide Help your child manage stress in various ways such as exercise, art, music, journal writing and practising mindfulness Talk to your child about puberty and expected body changes. Encourage questions Limit screen time to 2 hours per day, including watching television, messaging friends or playing computer games 	<ul style="list-style-type: none"> Begin taking charge of your health. This can include preparing your own healthy meals, remembering to exercise daily or taking your medicine on your own Keep track of your prescriptions, test results, and appointments with help from your family and your healthcare team Good oral hygiene is important, this includes brushing your teeth twice daily, flossing, and regular dental check-ups. Ask your cardiologist if you require antibiotics prior to dental or other procedures Talk about body changes and sexuality with someone you trust Find ways to help manage stress and/or anxiety (e.g., mindfulness, yoga, therapy/counselling, exercise, music) 	<ul style="list-style-type: none"> Plan ahead to fit your daily care into your schedule so you can hang out with friends, participate in sports and clubs and attend school Keep track of your appointments with an agenda or your cell phone Take charge of preparing and taking medications and/or following treatment plans on your own Know how your medications are paid for and how this may change when you turn 18 years old If you will be moving away from home, locate your local medical clinic, pharmacy and bloodwork lab, should you need them Make sure your healthcare team has your most up-to-date emergency contact information Talk about relationships and sexuality with someone you trust Find ways to help manage stress and/or anxiety such as mindfulness, yoga, therapy/counselling, exercise, or music 
Education	<ul style="list-style-type: none"> Read to your child regularly Tell all caregivers of your child's heart condition Praise your child for taking medication. Be sure to call it medicine, not candy Talk to your child about upcoming clinic visits. Bring along your child's favourite comfort item Be honest when explaining a procedure, even if it might hurt 	<ul style="list-style-type: none"> Encourage your child to read and spend time reading with them everyday When registering your child for school, speak with teachers about your child's healthcare needs If your child has difficulty with school work or in social situations consider seeking a formal assessment from your child's paediatrician or family doctor Teach your child about their heart condition Include siblings when your family talks about healthcare 	<ul style="list-style-type: none"> Keep track of your child's progress in school. If your child is not meeting grade-level expectations, seek support from their teacher Set "homework time" and expect your child to work independently Talk about your child's future – what do they want to be when they grow up? 	<ul style="list-style-type: none"> Learn and practice explaining your heart condition to teachers, camp counsellors and others who may need to know Develop a three-sentence summary, which includes the following information: <ul style="list-style-type: none"> Sentence 1: Age, diagnosis, and brief health history Sentence 2: Your cardiac care plan (e.g., history of cardiac procedures, medications, nutrition/exercise plan) Sentence 3: Questions or concerns to raise during the visit Take part in meetings about your education. Get to know your school guidance counsellor Talk about career interests and begin to set goals for after high school 	<ul style="list-style-type: none"> Find volunteer or part-time job opportunities. Go for career counselling, shadow someone at their job, attend a job fair Going to college or university? Ask your guidance counsellor for support. If needed, register with the Office of Special Accommodations/Disability Office/Access Centre on campus
Medical	<ul style="list-style-type: none"> Schedule regular visits with a pediatrician or family doctor for your child Learn about your child's heart condition, treatments and long-term outlook. Create a portable health summary with this information Know the emergency signs and symptoms associated with your child's heart condition Ask your child's pharmacist about medication dosage, schedule and side effects Plan ahead for travel. Have enough medicine/formula and take the most recent discharge summary or clinic letter with you Update your child's SickKids MyChart account 	<ul style="list-style-type: none"> Teach your child about emergency symptoms related to their condition. Reinforce with your child that these symptoms need to be shared with an adult immediately Tell your child about upcoming medical appointments If your child feels stress or anxiety about hospital visits, ask to speak with a Child Life Specialist Update your child's portable health summary Update your child's SickKids MyChart account 	<ul style="list-style-type: none"> Help your child understand more about their heart condition and its effects. Use pictures and reading material to help you explain, and visit kid-friendly websites such as kids.aboutkidshealth.ca Make sure your child knows about symptoms that need immediate medical attention Teach your child about their medications (e.g., medication name, purpose, dose, and schedule) Prepare for clinic appointments by making a list of questions and concerns with your child Let your child speak directly with the healthcare team. Encourage questions. Update your child's portable health summary Update your child's SickKids MyChart account 	<ul style="list-style-type: none"> Keep learning about your heart condition, symptoms that would need immediate medical attention, and reasons for tests or procedures Learn to plan ahead for being away from home by preparing any medication or equipment you might need Attend part of your medical appointments by yourself. Prepare a list of questions to ask Discuss getting ready to move to adult health care before you turn 18 years old Talk about birth control, drugs, alcohol and smoking/vaping with your healthcare team Create or review your portable health summary Update your SickKids MyChart account 	<ul style="list-style-type: none"> Be able to explain your heart condition to others including your diagnosis, treatment/surgeries and medications Take part in healthcare discussions with your healthcare team If you are sexually active, ensure you use a form of protection (e.g., condom) to prevent sexually transmitted infections Learn about the impact of your heart condition on pregnancy and genetics Speak to your cardiologist about options for birth control that are safe for you Discuss the effects of alcohol, smoking/vaping and drug use on your health with your healthcare team At age 18, your cardiac care will be transferred to the adult healthcare system. Speak to your healthcare team to arrange a visit to the adult setting and connect with others who have already transferred Learn more about your long-term cardiac outlook and future care plans Update your portable health summary Update your SickKids MyChart account