



Youth Transition Guide

**A guide to making the most out of your
transition to adult care**

Welcome Letter

You have reached the time to transition to the Virani Provincial Congenital Heart (VPACH) Program at St. Paul's Hospital. This period of transition is an important time of gaining independence as you prepare for adult care. For some young people, this period of transition and change can feel challenging, but we want to assure you that we are here to support you during this journey.

Your care might look different now. Here are some important things to know when you enter into the adult health care system.

Privacy and Consent

As an adult, details surrounding your care are private and your healthcare team will only discuss health information with others if you agree. Some young adults choose to involve family members, caregivers, or partners in their health care. To allow the team to share information with them, your consent is required.

How your care might be different from pediatric to adult care

Pediatric Healthcare Setting	Adult Healthcare Setting
Appointments may be longer.	Appointments may be shorter.
Environment is colourful and inviting.	Environment may lack colour and appear less inviting.
Your testing and appointment are often on the same day.	Your testing and appointment may be on different days.
Rich in resources. May be a one stop shop for all of your healthcare needs within the hospital.	You may need to access some supports in the community and through your family doctor. Your healthcare team can help you with this.
If you miss an appointment, someone from your healthcare team at BC Children's Hospital will call you to reschedule.	If you miss an appointment, you may not be contacted to reschedule. Always try to let the clinic know if you cannot make your appointment.
Your healthcare team will involve family/guardians in your care and will likely communicate with them when arranging appointments or making decisions.	You are welcome to bring a support person or family members with you to your appointment. They can be involved in your care as much or as little as you like, however your healthcare team would like to hear from you as you are the priority.
Pediatric healthcare teams are more directive in their approach.	Adult healthcare teams will consult with you to build a plan of care.
Routinely offer sedation for tests and procedures.	Sedation for tests and procedures is not routinely offered unless discussed with the team.

As a patient of our program, you have the right to:


- Be treated in a caring way
- Have things explained in a way that you understand
- Make your own health choices
- Have access to your medical information
- Bring a support person with you to your appointments

In turn, we want you to:

- Keep appointments or reschedule them as soon as you know you are unable to make the appointment
- Tell us about your current symptoms and health history to help us treat you
- Ask questions about your care
- Follow treatment plans that you develop with your doctor/health care team

Things you can do to support your transition to adult care:

There are things you can do to feel more prepared for adult care and to be more independent in your care and decision making. Before your first appointment, we recommend that you do the following:

-  <https://www.providencehealthcare.org/en/health-services/services/health-support-services/scotiabank-youth-transition-program#:~:text=Events,-Smooth%20Sailing%3A%20Let%27s>
- Bring your current medications with you to talk to your health care team about them.
- Getting medications from the pharmacy
- Getting bloodwork done
- Booking appointments.
- See your family doctor or nurse practitioner during this time so that they are aware of your transition to an adult team and can help support your health care needs, if required.

Things your parents/guardians can do to support your transition:

There are things your parents/guardians can do to feel more prepared for your move to adult care. Your parents/guardians may do the following:

- Attend the **Transition to Adult Care Workshop** to learn more about how youth can build confidence, skills, and knowledge during their transition to adult care. This workshop is only open to parents/guardians on select dates, so please review the schedule carefully when choosing a session.
To access the workshop schedule please visit the link under the "Events" heading:
<https://www.providencehealthcare.org/en/health-services/services/health-support-services/scotiabank-youth-transition-program#:~:text=Events,-Smooth%20Sailing%3A%20Let%27s>
- Review the **Frequently Asked Questions** (below). This will help answer some questions you may have about your child's transition to adult care.
- Talk to you about taking on more responsibility for your own care (e.g. getting medications from the pharmacy, getting blood work done, and booking appointments).



If you have any medical concerns while you are waiting for your first appointment in the VPACH clinic, you should contact your medical team at BC Children's Hospital. They will remain responsible for your care until your first clinic visit.

We are here to support you in your journey as you transition to adult care. Please let us know if you have any questions about this process or anything else related to your health care transition.

Sincerely,

Your team at the VPACH Clinic

You can contact us at:

Virani Provincial Adult Congenital Heart (VPACH) Program

Room 5051 - 5th Floor Providence Building
1081 Burrard Street, Vancouver, BC, V6Z1Y6

Email: pach@providencehealth.bc.ca

Phone: 604-806-8520

Fax: 604-806-8800

Please see Appendix A: on Page 11 for Team Contact Information.

Frequently Asked Questions (FAQ's): VPACH

Many young people transitioning to adult care have questions about what to expect and what's expected of them as an adult.

Below is a list of frequently asked questions (FAQ's) and answers about your care. If you have a question that is not listed below, feel free to ask anyone on your health care team.

Preparing for your move to adult care

Q. How can I build more independence in managing my health?

A. Building independence to manage your health is important as you enter into adulthood. Some young adults feel ready to be completely independent with their health care while other young adults feel like they still need some support, especially from parents and guardians. Although you may not be completely independent with your health care yet, you should start taking on more responsibility to better prepare for your future.

Building independence includes things like:

- **Decision making:** Come to your appointments well prepared for conversations about your health. This can help as you talk through your care options with your team.
 - Bring a list of questions or concerns about your health with you to your appointment. It's a great way to prepare for these conversations (see question examples on page 8).
- **Scheduling your appointments:** Maintain your own schedule and book your own appointments.
 - Set reminders for upcoming appointments in the calendar app on your phone or email.
 - Add your adult specialist and other health care providers and pharmacy information in the contacts app in your phone or email.
 - If you are taking transit to your appointments, check TransLink for transit information.
- **Attend appointments independently:** It is up to you whether you bring a support person to your appointment, but during your appointment, we want to hear from you.
- **Managing your medications:** Managing your medications is an important part of managing your health and building independence.
 - Store pictures of your medication labels on your phone to prepare for your appointments.
 - Check your pill containers for refills and always make sure you have one refill available.
 - Tip! use the calendar app on your smart phone to set reminders for refills.
 - Follow your medication plan. Talk to your parents and guardians about their medical and health benefits and decide if you need your own coverage.
 - If you take Special Authority Medications, talk to your adult care team about how to continue to get these paid for.
- **Keeping an ongoing health record:** Recording tests, procedures and medications can help you keep track of your health and health care.

If you are worried about how you are coping, it is important to speak to someone who can help you. A good place to start is your parents, guardians or your health care team.

Q. Are my health services confidential?

- A.** Your healthcare team will keep details of your care private and only discuss health information with others if you agree. However, there are some very limited situations when there is a requirement for healthcare providers to share your personal information. To learn more about health information privacy in British Columbia, please go to: <https://www.providencehealthcare.org/en/governance/accountability/privacy-confidentiality>



Q. How can I keep my parents or guardians connected in my care?

- A.** Your transition to adult care can be a challenging time for parents and families as they adjust to you growing up. A good way to keep your family connected during this time is to talk to them about your transition to adult care. Let them know what things you will be doing on your own and talk to them about ways they can support you. Having these conversations can help keep everyone feel more connected.

Q. What if I need to refill my prescriptions?

- A.** Depending on the medications you take you may have different doctors refilling your prescriptions. Your specialist doctor will usually only refill the medications that they prescribe. Other medications are usually refilled by your family doctor or nurse practitioner.
- Record which prescriptions are refilled by the health care team and which ones require a visit to your family doctor or nurse practitioner.
 - If urgent, your pharmacist may be able to refill your medication one time which will allow you more time to get a prescription refill from your doctor.

Q. I want to create a plan to document my health care wishes in case I were ever unable to express them on my own. How do I do this?

- A.** We encourage everyone to think about and talk about their future health. A good place to start is by having conversations with your close family, friends and health care provider(s) so that they know the health care treatment you would want in case you become incapable of expressing your own wishes. We also encourage you to write down your wishes. This is called an Advance Care Plan. For more information about this please go to: <https://www.providencehealthcare.org/en/welcome-information/advance-care-planning>



Q. How do I access my medical record?

- A.** As a patient, you have the right to access your medical information. If you just want to see information in your chart you can ask a staff member (e.g. physician, nurse) to review your medical record with you. They can help to interpret information and answer any questions you may have.



If you want a copy of your written chart, you can request a copy from Health Records Services. For more information about obtaining your health record, go to: <https://www.providencehealthcare.org/en/welcome-information/access-your-health-records>

Q. I'm a parent/ guardian, can I view my child's chart?

- A.** No, not without consent from the patient. Consent from the patient must be obtained and noted in the chart. If the patient is unable to give consent, then the person making the request must be the "substitute decision maker" before access can be given.



If you want to learn more information about a substitute decision maker please visit:
<https://www.providencehealthcare.org/en/welcome-information/advance-care-planning>

Your clinic visit

Q. What are the office hours?

- A.** The **clinic office hours** are Monday - Friday from 8:00 am - 4:00 pm. The office is closed on weekends and statutory holidays.

- Q.** The **VPACH clinic appointment times** are every Tuesday and Thursday, from 1:00 pm - 5:00 pm.

A. Are there after-hours call-in options?

If you call the clinic after hours there is voicemail available and you are welcome to leave a message. Calls will be returned on a priority basis. If you experience an urgent health concern, we request that you go to your nearest emergency department or call 911.

Q. What is the best way to contact my health team?

- A.** The best way to contact the VPACH team by phone or email.

Phone: 604-806-8520 (there is a phone tree that will direct you to nursing or clerical support)

Email: for general messages you can email the main VPACH email at pach@providencehealth.bc.ca, or you can contact one of the VPACH nurses by emailing pachnurse@providencehealth.bc.ca

Please be aware that the expected wait time for any non-urgent phone or email messages is 5 business days.

Q. How do I make, change, or cancel an appointment?

- A.** You can make an appointment by contacting our clinic by phone or email. If you need to adjust your appointment, please inform us as soon as possible so that we can make this appointment available for someone else.

In our clinic, we believe that patients are partners in their health care, and we'd like you to take the lead. If you are overdue for your clinic appointment and we haven't contacted you yet, please contact the clinic to request an appointment. Remember, we're partners in this!

Q. What should I expect at my first clinic visit and what's expected of me?

- A.** During your first appointment you will meet your adult cardiologist and your primary nurse. We will talk to you about what to expect as a patient of the VPACH clinic, and familiarize you with the clinic operations. We will also ask you questions to get to know you better, as well as talk to you about your health and wellbeing.

Prior to coming to your clinic visit, you will have your cardiac testing and imaging completed. This testing and imaging will be decided based on the recommended monitoring (or 'surveillance' in medical language) for your congenital heart condition. You will also complete a health questionnaire. This questionnaire will need to be completed before every visit in the VPACH clinic, and not just your first visit.

Q. What are some questions or topics I should discuss with my health care team?

A. Here is a list of topics that you might want to discuss with your health care team:

- How to manage your heart condition.
- How your heart condition impacts your daily life, such as school, work, physical activity, etc.
- How drugs, alcohol, tobacco or vaping affects your heart condition.
- How your heart condition affects your sexual health and family planning.
- What are some potential issues related to your condition and what can you do to reduce the risk of developing them.
 - For example, if you are more susceptible to irregular heart beats we would recommend that you limit your use of stimulants - like coffee!

Q. What do I need to know before I finish my appointment?

A. Before you leave your appointment you should confirm the following with your team.

- When is your next appointment.
- If you have been referred to another specialist.
- If you need additional imaging or lab tests.
- If you need a new prescription or need refills for your medication(s).
- Confirm that the office has your current contact information. Confirm that the office has your current contact information. If the office has your parents or guardians contact information, please provide your personal contact information also.

Q. Can I bring someone with me to my appointment?

A. Yes! You are welcome to bring a support person or family members with you to your appointment. They can be involved in your care as much or as little as you prefer, however your healthcare team would like to hear from you as you are the priority.

Your health care team

Q. Who is on my healthcare team, and what do they do?

A. We have many health care providers and administration support on our team to help you manage your heart condition and your health care. You can find more information about the VPACH team members and their roles in **Appendix A** of this guide.

Q. Who do I contact for questions about my health?

A. A good person to talk to about any heart-related questions is one of the VPACH nurses. They will provide you with advice and can speak with your heart doctor if your question requires a medical answer.

Q. Who do I contact for scheduling an appointment?

A. Call the main VPACH office at 604 806 8520 or email them at pach@providencehealth.bc.ca. You will be connected with an office administrator who can assist you with booking an appointment.

Q. Who do I contact for refilling my prescriptions?

A. If you need a prescription refilled that has been prescribed by the VPACH clinic, we can help you with that, but you may need an appointment for a prescription refill. Please contact the clinic at least 2 weeks in advance to schedule this visit. Please contact your family doctor, nurse practitioner, or other specialists for any refills not related to your heart condition.

Q. When should I contact my family doctor or nurse practitioner?

A. When you have a health condition that you see a specialist for, that specialist will provide the majority of care related to that condition, including ordering tests, prescribing medications, and determining a plan for treatment. However, it's important that you have a family doctor or nurse practitioner as well as they are an important part of your health care team.

Your family doctor or nurse practitioner can care for many injuries and illnesses and can help to arrange specialized care when needed. They also maintain your medical record and share medical information on your behalf with other care providers you are seeing.

Family doctors and nurse practitioners in BC provide a range of different service, which include:

- Treatment of common illnesses and injuries
 - Preventative care, including health promotion and disease prevention.
 - Basic emergency services
 - Youth health and lifestyle related health care (for example, smoking cessation, maintaining a healthy weight)
 - Mental health care
 - Immunizations
 - Pre-natal and maternity care
 - Referrals to/coordination with other levels of care (such as hospitals and specialist care)
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Q. How can I find a family doctor or nurse practitioner?

A. If you're looking for information about finding a family doctor or nurse practitioner in BC, go to: <https://www.healthlinkbc.ca/health-connect-registry>



Q. I've tried talking to my adult care team about issues with my care, but I don't feel like I'm getting the answers I need. What can I do?

A. If you feel like you have tried talking to multiple team members about your care and you still don't feel like you are getting the answers you need, you can consider talking to the Patient Care Quality Office.



To find more information about the Patient Care Quality Office go to:
<https://www.providencehealthcare.org/en/get-involved/compliments-complaints>

Q. What resources are available to help me as I transition to adulthood?

A. The following resources are available to support you as you enter into adulthood. If you can't find the right resource to meet your needs, talk to your healthcare team.

- **Scotiabank Youth Transition Program (SYTP)** <https://www.providencehealthcare.org/en/health-services/services/health-support-services/scotiabank-youth-transition-program#>
- **Foundry Virtual** (support with mental health, substance use, primary care): <https://foundrybc.ca/virtual/>
- **Financial Empowerment Program with Family Services of Greater Vancouver** (teaches financial literacy, helps to navigate government benefits and offers financial coaching): <https://fsgv.ca/programs/community-programs/financial-empowerment/>
- **Disability Alliance of BC** (support, information and assistance for people with disabilities): <https://disabilityalliancebc.org/>
- **Program Specific Resources:**
 - St. Paul's Hospital VPACH:** <https://www.providencehealthcare.org/en/clinics/virani-provincial-adult-congenital-heart-program>
 - iHeartchange:** <https://iheartchange.org/>
 - Canadian Congenital Heart Alliance:** <http://www.cchaforlife.org/>
 - Canadian Congenital Heart Network:** <http://www.cachnet.org/index.cgi>
 - Congenital Heart Disease Diagrams:** <https://www.congenital-heart-disease.ch/heart-disease>
 - Adult Congenital Heart Association:** <http://www.achaheart.org/>
 - Canadian Fontan:** <https://canadianfontan.com/>
 - Heart & Stroke:** <https://www.heartandstroke.ca/>

Acknowledgement

This document was developed by the Scotiabank Youth Transition Program (SYTP) working group at Providence Health Care. The SYTP aims to improve the transition process for young people and their families as they transition from pediatric healthcare services and into adult programs at St. Paul's Hospital.

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Patient Approved

This material has been reviewed and approved by patients, families and staff

Appendix A: Who we are and what we do

Role	Team member name	Best way to contact
Cardiologist:		
Nursing:		
Clinical Nurse Specialist:		
Social Work:		
Genetic Counselors:		
Pharmacist:		
Clerical Team:		