

Getting Ready for Adult Cardiac Care

Dear Teens and Families:

Congratulations! You are graduating from the McMaster Children's Cardiac Program or the Hospital for Sick Children in Toronto and will soon be receiving care for your heart at the ADULT CONGENITAL CARDIAC CLINIC located on the fourth floor, yellow section, The Boris Clinic.

As you get older, you may need to, or want to, take on more responsibility for keeping yourself as healthy as possible. This can be a time of mixed emotions. You have received care from the Hospital for Sick Children and/or McMaster Children's Hospital since you were really small. Moving apart from the familiar people and places that you know to a new adult health system may bring about feelings of excitement, fear, relief and sadness. It helps if you know how the adult clinic works and who works here.

It is important for you to know that as an adult, you still have cardiac care needs. These needs may be different for you as you get older. It is important for most patients with congenital heart defects to have life-long follow up. Some complications can take place later in life. It is much better to identify and deal with these in advance in order to help preserve the heart muscle function for a longer period of time. Visits with your adult congenital cardiologist on a regular basis will help to monitor your health status and to plan for the future.

Dr. Javier Ganame and Dr. Arsha Karbassi are the adult congenital Cardiologists that work in the clinic. Courtney Mitchell is the Registered nurse, Vicki Allan is the Administrative assistant and Nicole Matheson is the Business clerk.

There is ample literature that supports ensuring transition from Pediatric to Adult care within a year of the last pediatric appointment. This is to avoid young people getting lost to follow up, which is an important cause of significant problems in patients with congenital heart disease as they transition to adulthood.

You may wonder why you need a Cardiology consultation only one year after your last pediatrics visit, when you have been stable for the past few years and have only required visits every 2-3 years. You should not be alarmed by this, this does not imply that we are worried about you or that there is anything new wrong. It just allows us to see you within a year of your last pediatrics visit, and get to know you and get to know your cardiac anatomy. Remember we are seeing you in the ADULT CONGENITAL CARDIAC CLINIC for the first time, and our approach to ongoing follow up and management of your cardiac condition is different as you head into adulthood. Similarly, some of the tests that we do will be repeated such as a 2D echo, as our imaging is somewhat different than in childhood, and we do need to understand your anatomy and what has gone on previously especially if you have had surgery and interventions in the cath lab in childhood. It is best for us to get to know you when you are well and stable so that if anything happens in the next couple of years, we have a good baseline from which to compare.

Many things happen in the years following transition to adulthood. People move, go away to school, and change their lifestyle. There is good evidence that seeing patients

within a year of transition to adulthood improves their outcome and their compliance with medications and lifestyle recommendations. Therefore, you will be getting an appointment somewhere between 12-15 months of your last pediatrics appointment, mainly so that we can get know you, answer any questions going forward into your adult years and establish a new baseline for your ongoing cardiac care for the rest of your adult life. Between your pediatric appointment and your adult appointment a year or so later, you are still under the care of the Pediatric Cardiologist, and any questions or concerns should be addressed to them. Following your initial consultation, if all is stable and there is no reason to see you on an annual basis, we will reduce the frequency of your visits accordingly. This will be discussed with you in detail by the Physician and Nurse who see you at the time of your first visit.

A lot of information is available on the internet. We recommend that you use sites that are University affiliated, or referenced to a medical journal or book such as www.cachnet.org. To ensure that the information you find is accurate, keep a print-out of the website and discuss this at your visit. Some educational materials will be available to you in the adult clinic.

We hope that you find this information helpful, and look forward to being partners with you for your ongoing congenital cardiac needs.

Sincerely,

The Adult Congenital Cardiac Clinic

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Have you joined the Canadian Congenital Heart Alliance (CCHA)? CCHA is a congenital heart patient support and advocacy group that is working to ensure you get the best care and support to live a healthy life. We encourage you to join (it's free) so you can stay up-to-date with CHD-related news and events, have access to CHD educational material, and take part in both fun and educational events. We encourage your family to join too! Please visit www.cchaforlife.org for more information.