

Welcome to HSC Pediatric Chronic Kidney Disease Clinic

Introduction

You have been referred to the **Chronic Kidney Disease (CKD)** clinic at HSC Children's Hospital because you have kidney disease that requires a team who specializes in chronic kidney disease. This clinic cares for infants, children and youth up to 18 years of age who have more advanced kidney disease. Children referred to the CKD clinic have many different reasons why their kidneys are not working properly.

Clinic Goals:

- Provide expert team care to children with CKD.
- Teach patients and families with CKD.
- Help patients and families to learn to live well with CKD as part of their lives.



Where is the clinic?

The clinic is in Clinic Y of HSC Children's Clinic, 1st floor of Children's Clinic, Blue Dr. Goodbear Zone, HSC Children's Hospital, 840 Sherbrook Street, Winnipeg. Please arrive 5 minutes before your appointment to register with the Clinic Y desk. Clinic appointments usually take 2-3 hours for everyone on the team to meet with you and your child.

What should you bring to your first appointment?

Your child's medicines – It is important for you to bring all your child's medicines with you to each clinic visit so we can make sure your child is receiving the right type and amount of each medicine. That way we can make the correct changes to the medicines if needed.

A 3-day food record – Write down everything your child eats or drinks for three days including the amounts of what they eat. The dietitian will use this as a baseline of your child's nutrition to ensure ideal nutritional intake.

Any questions or concerns – We welcome your ideas and questions as each caregiver and family is a big part of the team. It can be helpful to write these down ahead of time to discuss with us at each appointment.

What should you do before coming to clinic?

Blood work – we ask that you have blood work done within the week **before** coming to your appointment. This allows us to review the results and make any needed changes to your child's care during the clinic visit.

Blood tests can be done in the Children's Clinic Lab or at your local lab. Please discuss the options with the nurse clinician.

The nursing assistants will arrange to have any blood test or urine requisitions waiting for you at the front desk of Children's Clinic, or sent to your local lab.

Who will you meet and what do we do?

Each person at CKD clinic is a specialist in CKD and has a role in helping you live with the illness. Together we are called the CKD team.

Nephrologists (Kidney Doctors) – You will see one of the kidney doctors. These doctors share the care of children in this clinic and communicate about your child’s care to all team members. From time-to-time medical students and resident doctors may see your family.

Nurse Clinician – The nurse clinician will coordinate and oversee your child’s care. The nurse clinician will be your contact person outside of clinic times if you have questions or concerns. They are responsible for teaching patients and families about chronic kidney disease, tests and procedures children need, medications used in CKD and to act as an advocate for families. If your child needs to start dialysis, the nurse clinician will be involved in helping you decide which type of dialysis is right for your child and family. The nurse clinician will organize starting hemodialysis and teaches families how to do peritoneal dialysis at home.

Clinic Nurse – The clinic nurse begins the visit by checking your child’s weight, height and blood pressure and reviewing all medications. They work with the nurse clinician to help coordinate your child’s care and immunizations.

Dietitian – The dietitian is an expert in nutrition and finding the right combination of foods for people living with kidney disease. They review your child’s diet, blood work and growth to develop a plan for any special dietary needs. This is to make sure your child has the proper nutrition for their type of kidney disease.

Social Worker – The social worker will help you access supports and counsel you in coping with difficulties related to having a chronic illness such as CKD. There are times a family may have to move to Winnipeg for CKD care and this can be very stressful. The social worker can help with financial support, housing applications, school registration/communication and other community resources.

Transplant Coordinator – The transplant coordinator is responsible for teaching you about kidney transplants, and coordinates tests and appointments needed before having a kidney transplant. You may be referred for a kidney transplant assessment when the CKD team feels your child needs this and is ready for this assessment.

Nursing Assistant – The nursing assistant will book your child’s appointments and coordinates other tests and appointments.

When you come to the clinic, the unit assistant will check your phone number, address, other contact information and confirm which pharmacy you use. It is important that we are able to contact you with changes to your child’s kidney care. Let the unit assistant at the desk know of any changes at each visit.



Other tests your child will have as part of the CKD clinic:

Children with chronic kidney disease may need a variety of tests over time to check their overall health and manage symptoms.

These tests may include:

EKG/Echocardiogram – These tests look at the structure and function of the heart. These tests are done once a year at the Children’s Heart Centre on the fourth floor of Children’s Hospital.

Viral Serology – Once a year your child will have blood taken to check for risk of diseases caused by viruses. This helps the team know if more immunizations are needed. Immunizations are very important for a future kidney transplant. These blood tests will be taken at the same time as the regular blood tests.

Chest X-ray – this X-ray is done as needed and before transplant to check your child’s lungs and heart.

When will your child be seen again?

Your child will be seen every 4-8 weeks for appointments. If you live far away from Winnipeg, we can sometimes do virtual clinic appointments so that you don’t have to travel as much. Talk to us at the clinic if you are interested in this option. This would not be for every clinic as we do need to see your child in person at times.

Who should you call if you have problems?

If you have questions about medical issues between appointments, please call the nurse clinician at **204-787-4656**. They are your first contact person and coordinate your child’s care. The nurse clinician will be able to answer your questions and will let the doctor know of any concerns.

If you have an urgent medical question during the evening, weekend, after hours or during holidays, phone hospital paging at **204-787-2071** and ask for the Pediatric Nephrologist-On-Call. They will call you back and be able to help you.

