

MANITOBA RENAL PROGRAM PATIENT HANDBOOK

FOR NEW IN-CENTRE HEMODIALYSIS PATIENTS



MY INFORMATION

My nephrologists: _____

My social worker: _____

My dietician: _____

My pharmacist: _____

My dialysis schedule:

Morning _____

Afternoon _____

Evening _____

Monday – Wednesday – Friday _____

Tuesday – Thursday – Saturday _____



ABOUT MANITOBA RENAL PROGRAM

WELCOME TO IN-CENTRE HEMODIALYSIS

This handbook can help answer questions you may have about your in-centre hemodialysis treatment and help you understand the change taking place in your medical care. As you adjust to your new treatment plan, we want you to know that we are here to help. Your Manitoba Renal Program (MRP) health-care team is a resource for you in addition to this book, other materials you received in Renal Health Clinic and the MRP's website: www.kidneyhealth.ca. If you have any questions or concerns, don't hesitate to ask your nephrologists, nurses, dietitians, pharmacists, social workers and support staff.

General Rules

We try to respect your confidentiality. Due to a lack of space between dialysis stations, sometimes information may be overheard. We ask that you respect the confidentiality of other patients by not sharing any information you happen to overhear.

You have a set appointment time that health-care staff try to honour but sometimes you may not be called to come in at the exact time of your appointment. We ask you to be patient and we will have you in as soon as we can.

Patients are not provided meals during dialysis. Unless there is an exceptional circumstance, patients should bring their own snack.

Please refrain from wearing perfume, cologne or body spray when you come for treatment and please ask your visitors to abide by this rule as well. The hospital is scent free.

Patients and staff are entitled to a safe environment free from any form of discrimination or harassment. Physical, verbal or mental abuse or violence will not be tolerated and will be dealt with according to hospital policy.

Patient Transfers

While we do our best to serve you at your hospital of choice, there is a growing need for dialysis in Manitoba. Hemodialysis units may become full and be unable to start new patients. When this happens, patients already on dialysis will have to transfer to another dialysis unit in the city. You may be:

- Transferred to another centre in Winnipeg
- Have your time changed at your centre
- Transferred to another centre and have your time changed.

This means that while MRP may start you at a specific dialysis unit, and will do its best to have you on a consistent dialysis schedule, it is not guaranteed you will continue to receive care at that unit in the future. Because of the growing rates of kidney disease, MRP dialysis units can be very busy and, at times, full.

In Winnipeg, St. Boniface Hospital, Seven Oaks General Hospital and Health Sciences Centre accommodate our new, urgent dialysis patients. Because of space restrictions and the start of these new patients onto dialysis, there may be times when we have to transfer patients already on dialysis at these units to another dialysis centre. All MRP dialysis centres provide the same standard of quality patient care and your dialysis care records will travel with you to the new site.

As outlined above, your dialysis shift might also change.



PATIENT RIGHTS

YOU HAVE A RIGHT TO:

- be informed about your care
- be treated with respect and dignity
- review your chart (in-patients can see their chart within 24 hours, out-patients can make a request and pay a fee to Medical Records to see their health information)
- speak to any member of the interdisciplinary team as needed
- ask questions and get answers in a timely manner
- a second opinion if you wish to seek one
- ask about your health care provider's experience and credentials
- to take action if you are not satisfied with the care you or someone you care about receives - the first step is talking with your caregiver or supervisor

PATIENT RESPONSIBILITIES

YOU HAVE THE RESPONSIBILITY TO:

- be an active participant in your care
- treat other patients, staff and visitors with respect and dignity
- tell your health care team about changes in your health or medication, address, phone number or Manitoba Health Number
- arrive for treatment on time or tell us if you cannot get to the unit on time
- follow the health-care team's recommendations regarding medications, fluid limits and diet choices or let the doctor know if for some reason you cannot

TYPES OF TREATMENT

If you are interested in other treatment options, talk to your doctor or nurse. They will help assess which treatments are suitable for you and offer you more information on your options.

In-Centre Hemodialysis

Hemodialysis is when blood is cleaned outside of the body using a machine. In-Centre hemodialysis treatments are scheduled three times a week at a dialysis unit in a health-care facility. This is the treatment you are currently using.

Peritoneal Dialysis

Peritoneal dialysis (PD) is a form of dialysis done at home either by the patient, a caregiver or home care. It is similar to hemodialysis, but the blood is cleaned inside your body rather than outside in a machine. It is a more gentle form of dialysis, therefore your kidneys hold onto their remaining function longer. A patient choosing PD dialyzes seven days a week. PD is relatively simple to learn and do and most patients are easily able to do their own PD after five days of education and training provided by a nurse in the PD unit. Peritoneal dialysis allows for a significantly less restricted diet, greater flexibility in one's personal schedule, and greater ability to travel. You only need to visit the PD clinic every three to four months for assessment by team members.



Home Hemodialysis

This option is only suitable for some patients. You and your partner are trained to perform hemodialysis at home. Your home will be outfitted with a hemodialysis machine and you will be able to set your own dialysis schedule. Once training is complete, you only need to visit the home hemo clinic once every one to two months for assessment by team members. There are additional benefits to a patient's health when on home hemodialysis in comparison to in-centre hemodialysis because home hemodialysis is done more frequently. Benefits also include independence, a flexible schedule and for nocturnal home hemo: a less restricted diet and improved blood pressure.

Transplant

If you are interested in receiving a kidney transplant, talk to your doctor or nurse. Manitoba has its own renal transplant program that performs both living and deceased donor transplants for people with kidney disease. Individuals must be considered eligible for a kidney transplant by their Nephrologist before being able to be seen and be evaluated by a transplant physician. There is a waiting list for kidney transplants in Manitoba.

End of Life Care

You have the right to choose no dialysis or treatment. If you choose no treatment, you will die. This can be a very difficult decision but sometimes your quality of life on dialysis might not be what you expect, or is worse. You may want to try dialysis for a trial period to see if it makes you feel better. You have the right to stop treatment if you are mentally able to make that decision. Our renal team will continue to offer care and support and connect you with additional support if you decide to do this.



HEMODIALYSIS IN HOSPITAL

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YOUR FIRST DAY

What to Wear

Wear comfortable, washable clothes that allow for your access site to be easily reached. Examples include button up shirts for catheters and short-sleeve shirts for a fistula or graft. There are also hospital gowns available. Blankets can be provided to help make you more comfortable.

Getting There

For your first three to six treatments it is best to have someone drive you instead of driving yourself. You may feel tired or light-headed after dialysis initially, but once you become used to dialysis, you may start driving yourself. If you are unable to drive, your health-care team may be able to refer you to a variety of transportation services available to you.

Waiting Area

Please remain in the waiting area until a member of the dialysis staff calls you for your appointment. We want to ensure your station is clean and ready before you receive care.

Valuables

Keep your valuables with you at all times. MRP, and the health-care facility, cannot guarantee the security of your items.

Hand Hygiene

In order to help stop the spread of bacteria in the unit please carefully wash your hands or use hand sanitizer before entering the unit and after leaving. This will help keep you and keep all of our patients healthy.

Phones

Cell phones should not be used while on the unit. There are patient phones available in the waiting area of the unit.

Entertainment

For entertainment there are televisions at each station but you should bring your own headphones to listen to the TV. Some patients read, sleep, visit, write or listen to music while receiving dialysis. Some units have volunteers who visit to talk or play cards/games with patients. Talk to your nurse or social worker if you would like a volunteer to visit.

Food & Drinks

Eating on dialysis is not recommended because it can cause a drop in blood pressure and seriously affect your treatment. Some people may wish to bring a healthy snack to eat when treatment is over. Your renal dietician can provide more information about suitable snacks.

Bathroom Breaks

It is best to train your body to have bowel movements before your treatment. The need to go for a bowel movement while on dialysis can have serious, harmful effects during your treatment by affecting blood pressure. Washrooms are available to use before and after treatment. If you really need to go while receiving dialysis a bedpan will be provided. If you are having constant issues with constipation or diarrhea, make sure to talk to your doctor or nurse.

Your Access Site

During hemodialysis, a small amount of blood (1 cup) is pumped out of the body and returned back to the body at a very fast rate. In order to accomplish this, a vascular access is required. Vascular accesses are pathways to the blood stream created by vascular surgeons. The different types of vascular access are graft, fistula and central catheter. You will be given information on how to care for your access. It's very important to properly care for your access site in order to prevent infection. Signs of infection include redness and/or tenderness at the site, and/or fever. If you have concerns or questions, ask your nurse for information about caring for your access site.

Dialysis Routine

Your weight, blood pressure and temperature are taken before and after treatment. Skin around your access site will be cleaned with antiseptic. During treatment your nurse will regularly check in with you. If you experience any unusual feelings during or after treatment, such as lightheadedness, headache, dizziness, nausea, blurred vision, loss of hearing or leg cramps, notify your nurse immediately. You need to keep your access line visible during treatment.

DURING DIALYSIS

Your Station

You may not get the same station each time you dialyze due to the fact we must accommodate the changing needs of all patients and keep patients safe. If you have a safety concern for yourself about any station, please discuss this with your nurse.

Infection Control

Your health-care team takes all precautions to limit the risk of infection in the dialysis units. Equipment is disinfected regularly. Dialysis tubes and filters are only used once then thrown away. Staff wear protective equipment and wash their hands between caring for patients. Please talk to your nurse if you are worried about any procedure and the risk of infection.



YOUR SCHEDULE

Initially you are likely to be scheduled into a day spot until you are comfortable with dialysis and can be moved into an evening spot. Your health-care team will try to accommodate schedule requests but cannot guarantee anything. Factors that may affect requests for permanent schedule changes are level of wellness, transportation needs, employment/work status, home care services, how long the request has been in and how long you have been on hemodialysis. If you need to switch your treatment time for a special occasion please call the unit. If you are going to be late for your treatment time please call the unit and let them know when you will arrive.

Missing or Stopping Dialysis

You should not skip or shorten your treatment if at all possible. Regular dialysis is necessary for your overall health. If you are sick, it is important that you still come to dialysis. You have the right to make your own choices about your treatment as long as you are mentally well, which means you can refuse or stop dialysis permanently. If you choose to stop or skip a treatment, you may put your life in danger. Please speak to your doctor about this. If there are other issues in your life that are affecting you, please talk to a renal social worker.

Bad Weather or Emergencies

If there is bad weather or another emergency that is preventing you from getting to your dialysis appointment, call the unit and let them know.

GENERAL HEMODIALYSIS INFORMATION

MEDICATION

During your visits to Renal Health Clinic, your health-care team will have monitored your medications. Once you start dialysis your Nephrologists, pharmacists and nurses will review your medications and their dosages. Staff will explain any changes to you. If you have changes made to your medication by another doctor, tell the nursing staff. Your renal pharmacist is a part of your health-care team and is available if you have any questions about your medications.

Non-Prescription Medications

Always talk to your pharmacist, doctor or nurse before taking non-prescription medications such as laxatives, antacids, pain pills or herbal remedies. These can be harmful to people on dialysis. Always notify your nurse or pharmacist if there is any changes in your medication or if you no are longer taking a medication.

Your List of Medications

Bring your list of medications with you if you are going to the emergency room, admitted to hospital or have an appointment with a doctor.

EATING & DRINKING

As mentioned before, eating on dialysis is not recommended because it can cause a drop in blood pressure and seriously affect your treatment. Some people may wish to bring a healthy snack to eat when treatment is over. Your renal dietician can provide more information about suitable snacks. Every person has different needs and restrictions when it comes to foods and liquids. Your renal dietician will talk to you about what you can and should be eating. They will also let you know what foods you should be avoiding. Always talk to your dietician if you have concerns about your nutritional needs. As well, MRP has a limited amount of kidney friendly cookbooks available through our main office or your renal dietician. Additional resources and information can be found on our website: www.kidneyhealth.ca.



PROBLEMS OR CONCERNS

Medical Problems While at Home

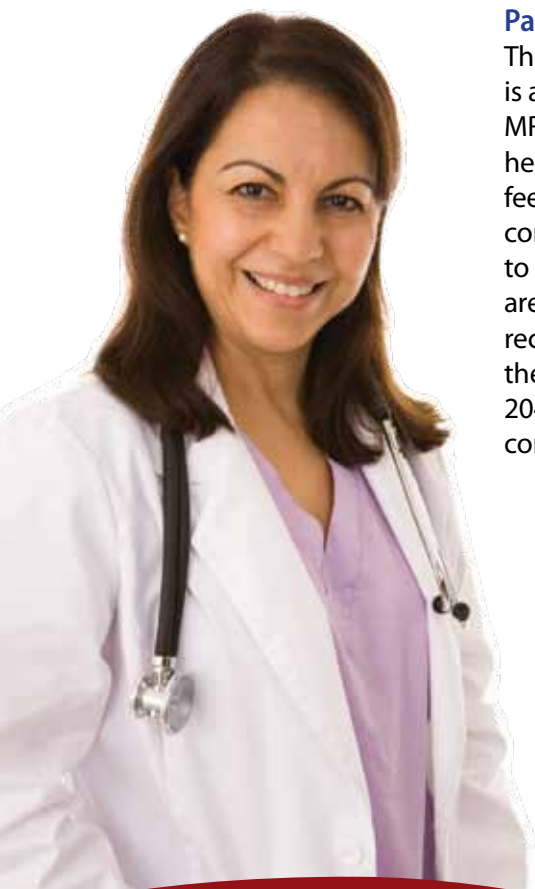
If you experience health issues while at home call the dialysis unit. If you have a serious concern, go to your local hospital's emergency department. Make sure they know you are a hemodialysis patient.

Renal Social Worker

Your renal social worker is available to help you understand and adapt to lifestyle changes that come with dialysis. If you are having issues with your care or in your personal life, the social worker can help connect you with useful resources. Some areas the social worker may be able to help with are counseling, education, helping address social and financial concerns, employer consultations, home care referral and vacation planning.

Patient Representative Committee

The MRP Patient Representative Committee is a committee formed by patients with an MRP coordinator. Regular meetings are held to discuss patient concerns and get feedback. Information gathered from the committee is shared with MRP management to help resolve issues or concerns. Patients are not obligated to attend any meetings but receive a small honorarium for every meeting they attend. Call our Patient Coordinator at 204-787-3286 to find out more about the committee and the next meeting.



FITNESS

Exercise is essential to keeping our bodies and minds healthy. Maintaining an active lifestyle is particularly important for patients with kidney disease. It is key in having more energy to do daily activities. Unfortunately, people with kidney disease often become less active. The benefits of staying active include improved energy, muscle strength, flexibility, blood pressure, stronger bones, blood sugar levels and dialysis quality. Patients should always check with their doctor before beginning new exercises and activities.

In Winnipeg, Brandon and some rural units, MRP has exercise programs for patients with kidney disease. To learn more call our Fitness & Wellness Coordinator at 204-631-3039. Patients outside of Winnipeg can also talk to their doctor and nurse about resources within your health-care facility and community. Also go to www.kidneyhealth.ca for more information.



YOUR HEALTH-CARE TEAM

During your Hemodialysis Unit visits and within your dialysis units you will meet and work with several of our health-care team members. The following is a brief description of each role.

Unit Clerk – The ward clerks manage information on your medical chart, book appointments and tests for you, and help with organizing dialysis schedules, answering questions and day-to-day unit operations.

Unit Assistant – Aides help set up dialysis machines and supplies and clean and disinfect the machines after patients are done.

Nurse – The nurse receives special training to provide you with your care and treatments. They are responsible for your well-being during dialysis and can help with any questions or problems you have. Nurses assess patients before, during and after dialysis and make suggestions for changes that may help you feel better and keep you safe.

Dietician – Renal dieticians talk to you about what food choices are best for your health. Every person's diet will be different and a dietician will talk to you about your specific needs and make suggestions that may help you feel better. This might include information on protein, fluid, potassium, salt, calcium and phosphorous. If you have questions, contact your renal dietician to make an appointment or ask your nurse to help you set up an appointment.

Doctor – A kidney doctor (Nephrologist) gives medical care and adjusts your dialysis prescription as needed. The doctor will be on the unit regularly and can otherwise be contacted by nurses if there is a problem. One kidney doctor provides all the medical care in the hemodialysis unit and at the beginning of every month a new doctor is assigned to the unit. This may be new for patients who are used to seeing the same doctor in the kidney clinic for many years. Any medical forms that need to be completed for you will be completed by the doctor in the dialysis unit that month. Please advise any of your other health care providers to address all letters and communication to that doctor.

Educator – A nurse educator teaches nurses and dialysis aides about new equipment, procedures and techniques. The educator also may help with problems or concerns that come up during dialysis.

Manager – The manager supervises staff and makes sure your treatments are given safely according to rules and guidelines of MRP. The manager also helps with problems or concerns.

Pharmacist – A pharmacist keeps an updated records of patients' medications, helps patients understand the medications prescribed and helps doctors choose the right medications. Tell your nurse, if you would like to speak to a pharmacist about your medications.

Social Worker – A renal social worker can help you and your family adapt to lifestyle changes that come with your kidney disease. If you are having issues with your care or in your personal life, the social worker can help connect you with useful resources. Some areas the social worker may help with are counseling, education, helping address social and financial concerns, employer consultations and vacation planning. You can make an appointment whenever you need by calling your renal social worker.

Fitness & Wellness Coordinator – The renal fitness and wellness coordinator is based in Winnipeg and helps develop exercise programs and techniques that are suitable for individuals living with kidney disease and/or are on dialysis.

Technologists – The technologists take care of the operation and safety of our dialysis machines and other health-care equipment. They also take care of the water treatment system necessary for a dialysis program.





ADDITIONAL INFORMATION

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VISITORS

You may have up to two visitors at a time. We ask that visitors wait until you have started your dialysis before they enter the unit, and waits in the waiting room while you finish up. All visitors should wash hands or use hand sanitizer before entering and after leaving the dialysis unit. Please make sure your visitor's are respectful and do not interfere with unit staffs' duties. Visitors who have cold or flu-like symptoms should not visit.

VACATIONS

Patients who want to travel have to plan in advance. If you are planning a vacation let your nurse and social worker know as soon as possible. We will try to help you arrange dialysis treatments at a unit near your destination if it's in Canada. Travel within Canada requires at least six to eight weeks notice. There are no additional costs to receive dialysis at other units in Canada (with the only exception being private clinics in Quebec).

Travel outside of Canada requires longer notice. It is up to you or your family to make initial contact with the dialysis centre to arrange dates for dialysis. At that time you can ask the unit to send transfer forms to us for completion. Tests are often required for this process so please allow plenty of time for these to be organized. Units outside of Canada charge various fees that are the responsibility of the patient. Be sure to get the costs or additional fees in writing beforehand. You must assume all the costs of the dialysis treatment outside Canada but can provide receipts to Manitoba Health for a set amount of reimbursement, which is usually only a portion of each dialysis treatment.

There are vacation destinations that specialize in providing dialysis services to their guests such as Camp Dorset in Ontario and various cruise lines and Caribbean resorts. As well, Fresenius Medical Care offers tips and information for no charge when you call their Patient Travel Service office at 1-866-434-2597.

YOUR FAMILY DOCTOR

You should continue to see your family doctor for problems not related to your kidney disease. Let your nurse know if your family doctor has put you on any new medication or has referred you to a specialist. If you see a specialist or have a test done, ask that copies of the report be sent to both your family doctor and the dialysis unit.

SURGERY

If you need to have any type of surgery please let your nurse know. We may need to change your scheduled dialysis and/or make sure medications used for dialysis do not interfere with surgery. If you are having out of town surgery, tell your nurse as soon as possible so arrangements can be made.



SUPPORT

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There are a variety of supports and resources for individuals living with kidney disease.

Manitoba Renal Program has many resources and tools available for you online at www.kidneyhealth.ca. As well, Manitoba Renal Program has educational events to help bring together patients and provide information. Our Patient Representative Committee is a place where patients can share their concerns and be heard. More information on this committee is found in the “Problems & Concerns” section. Your renal social worker can also help connect you with supports in your community.

The Kidney Foundation of Canada – Manitoba Chapter has an active community of individuals raising awareness of kidney disease and providing support to individuals with kidney disease. Their wide range of resources includes brochures and booklets, events, support groups, peer groups and online tools. Call 204-989-0800 or 1-800-729-7176 to find out how they can assist you, or visit their website at www.kidney.ca.

Manitoba Renal Program works to prevent kidney disease, promote kidney health and provide kidney health services to Manitobans.

For more information contact

Manitoba Renal Program:

A570 Seven Oaks General Hospital

Phone: 204.632.3607

Fax: 204.632.6168



kidneyhealth.ca
manitoba renal program



Winnipeg Regional
Health Authority
Caring for Health

Office régional de la
santé de Winnipeg

À l'écoute de notre santé