



## Minimal Change Disease

### What is it?

Minimal Change Disease (MCD) is one of a larger group of kidney diseases known as glomerulonephritis (GN). MCD is a condition that affects the glomeruli – the tiny filters in the kidneys responsible for filtering waste and excess fluid from the blood. MCD is one of the causes of nephrotic syndrome, a condition where too much protein leaks into the urine.

### Here's what happens in MCD:

- The kidneys' filters (glomeruli) become injured, which is thought to be caused by an immune system problem. Specifically, the body's immune system mistakenly attacks the filters of the kidneys, causing them to become leaky.
- The leaky filters allow protein, especially albumin, to escape into the urine (this is called proteinuria). Normally, this protein would stay in the blood.
- As a result, the levels of protein in the blood drop, leading to fluid buildup in the body, which causes swelling (edema), especially in the legs, ankles, and around the eyes.
- The injury to the kidneys is often reversible with treatment, but if left untreated or if the disease recurs often, it can lead to kidney problems over time.
- Minimal change disease gets its name because there are minimal changes seen on routine kidney biopsy (as opposed to other forms of nephrotic syndrome, such as focal segmental glomerulosclerosis (FSGS), IgA nephropathy, or membranous nephropathy). The injury to a specific cell in the glomerulus called the podocyte can only be seen by a special high-powered microscope.

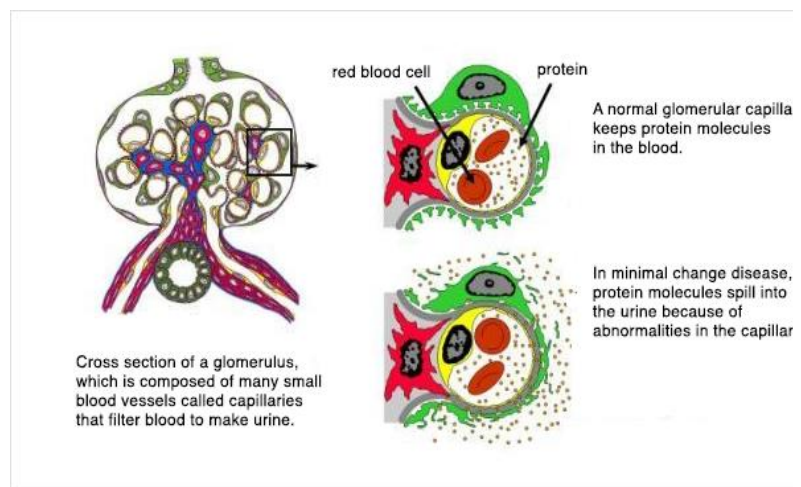


Figure source: <https://unckidneycenter.org/kidneyhealthlibrary/glomerular-disease/minimal-change-disease/>

### The symptoms of MCD usually come on suddenly and may include:

- Fatigue (feeling tired).
- Swelling (edema) – puffiness in the legs, ankles, feet, and/or around the eyes.

### The complications of MCD may include:

- A sudden decline in your kidney function, which often recovers.
- Elevated cholesterol (fats) in your blood.



- Foamy or bubbly urine – due to excess protein leaking into it from the kidneys.
- Weight gain – caused by fluid retention, not actual fat gain.
- Loss of appetite.
- More frequent infections – the immune system may not work as well due to protein loss.
- High blood pressure – the kidneys help regulate blood pressure, so damage to the kidneys can cause it to rise.

### What happens after you have been diagnosed with MCD?

After your kidney biopsy is reported and a final diagnosis of MCD is made, your kidney doctor (nephrologist) and/or kidney care team may order further tests or scans and will discuss appropriate treatment with you. In children, a kidney biopsy is sometimes not necessary.

### How is MCD treated?

#### General measures:

- Diuretic medications ("water pills") – help remove extra fluid from the body to reduce swelling.
  - Sometimes intravenous albumin infusion can be required for diuretics to work.
- Low-salt diet – eating less salt helps prevent swelling and fluid buildup.
- Fluid restriction (drinking less fluids) may also be necessary to prevent swelling.
- Blood pressure and cholesterol medications – some people may need medicine to control blood pressure and cholesterol.
- Lab tests: Your kidney doctor and/or kidney care team will follow you closely with frequent urine and blood tests to monitor your response to treatment and help you manage any symptoms.
- Antibiotics during immunosuppressive therapy: If you are receiving immunosuppressive therapy, depending on its type, you may be started on a combination of trimethoprim and sulfamethoxazole. These antibiotics are used to reduce the risk of very serious infection that can occur in patients on medications that reduce the immune response.
- Medication options: Your kidney doctor and/or kidney care team will support you in learning about the medication options that would be best for you.
- Medication cost: BC Renal covers the cost of a wide range of medications used for MCD treatment.

#### Immunosuppressive (active) therapies:

##### Options include:

- Prednisone
- Tacrolimus
- Mycophenolate mofetil
- Cyclophosphamide
- Rituximab

During immunosuppressive (active) therapy, you are at a higher risk of bacterial and viral infection. If you develop a fever, please seek medical attention immediately.



- **Important:** Patients need to check with their kidney doctor and/or kidney care team before taking any over-the-counter (OTC) medications and natural health products.
- **Important:** Patients with chronic kidney disease like MCD need to keep their vaccinations updated. Some treatments may reduce the effectiveness of vaccination. You are encouraged to discuss with your kidney doctor and/or kidney care team what vaccinations may be appropriate for you.
- **Important:** Pregnancy may impact kidney function. If you are planning a pregnancy, please consult with your kidney doctor.
- **Important:** Smoking cessation is important – it can help slow down the worsening of kidney disease. Your family doctor can provide resources to help quit smoking.

### Living with MCD

- **Support of kidney care team:** BC kidney patients registered with BC Renal have access to a comprehensive kidney care clinic (KCC) team that includes nurses, dietitians, and social workers. In most cases, patients will also have access to a pharmacist.
- **Support for your wellbeing:** It will be important for you to stay active and healthy. The Kidney Foundation's online Kidney Wellness Hub (<https://kidneywellnesshub.ca/>) has a lot of useful information. It covers staying active, eating well, mental wellbeing, and socially connecting, including peer support groups. It also provides online classes, webinar recordings, and activity suggestions for patients of all ability levels.
- **Ongoing follow-up:** Most people begin to feel better within a few weeks, though some may require more time to fully recover. It's important to note that relapses can occur over the long term:
  - Some individuals experience only a single episode of the disease that requires one course of treatment.
  - Others may have infrequent episodes, which are treated as they occur.
  - Some may face more frequent relapses and require longer or more intensive treatment.
  - Ongoing follow-up with your kidney doctor and/or kidney care team will be essential.
- **Relapses due to respiratory and other infections:** Please note that respiratory and other infections could trigger a relapse in the disease, and a sign of relapse may be visible as foam in the urine and/or swelling. Consult with your doctor as early as you see foam in the urine, or you start to have swelling after an infection.
- **Risk of kidney failure:** Kidney failure is unusual with minimal change disease. If your kidneys fail, your treatment options may include transplant, dialysis, and conservative care<sup>1</sup>. However, a very small portion of MCD patients

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<sup>1</sup> Conservative care, sometimes called conservative kidney management (CKM) or supportive kidney care, focuses on treating the symptoms of kidney failure to make you feel as well as possible. It does not treat the causes or attempt to cure kidney failure. Although conservative care does not include dialysis or transplant, it does include all of the other parts of kidney care and support from your team. For more information see this BC Renal's handout: [http://www.bcrenal.ca/resource-gallery/Documents/Patient\\_Guide-Transitioning\\_to\\_Conservative\\_Care-Kidney\\_Care\\_Clinics.pdf](http://www.bcrenal.ca/resource-gallery/Documents/Patient_Guide-Transitioning_to_Conservative_Care-Kidney_Care_Clinics.pdf).



may experience recurrences of the disease even after transplantation. Your kidney doctor and/or kidney care team will be there to educate and support you throughout your journey.

- Participation in clinical trials: Sometimes, people living with MCD may be invited to participate in a clinical trial for new therapies and medications. If you choose to volunteer in a trial, your kidney doctor and/or kidney care team will help you navigate the process.

### **Further information**

- There may be a lot of confusing information about MCD and other kidney diseases on the Internet. The following websites are good sources of information for people living with this disease:
  - The Kidney Foundation of Canada - <https://kidney.ca/>
  - Kidney Wellness Hub - <https://kidneywellnesshub.ca/>
  - BC Renal GN web page - <http://www.bcrenal.ca/health-info/kidney-care/glomerulonephritis>
  - Minimal change disease webpage – by Glomcon.org - <https://www.glomcon.org/kidney-diseases/minimal-change-disease>
  - Minimal change disease video – by Osmosis.org - [https://www.osmosis.org/learn/Minimal\\_change\\_disease](https://www.osmosis.org/learn/Minimal_change_disease)
- If you continue to have questions about your condition or treatment, please keep track of these questions and ask your kidney doctor and/or your kidney care team.