

Myeloma Canada

InfoGuide Series

Myeloma and the Kidney





MYELOMA CANADA

MAKING MYELOMA MATTER

www.myeloma.ca



Introduction

This InfoGuide is written for patients with myeloma, their families and friends. It explains the role of the kidneys, why and how myeloma may affect the kidneys, the symptoms of kidney disease and how it is diagnosed and managed.

Kidney disease can occur for many different reasons. The kidney disease referred to in this InfoGuide is specific to the damage caused by myeloma and is referred to as "myeloma kidney disease".

In this InfoGuide we refer to "the kidneys". However, the word "renal," referring to the kidneys, is also commonly used by doctors. The terms "renal disease" and "renal damage" mean the same as kidney disease and kidney damage.

Some of the more technical or unusual words **appear in bold** the first time they are used and are explained in the glossary on page 20.

As you read through this InfoGuide, you may refer to the "More Detail" boxes to read more about selected topics and the "Self-help" boxes if you want tips on how to make your healing journey easier.

Aims of this InfoGuide

- To help you understand more about what the kidneys do and what happens when the kidneys are damaged
- To help you understand how myeloma kidney disease is managed
- To provide information to caregivers and family members

Myeloma Canada also has other educational material available, including the *Multiple Myeloma Patient Handbook, Myeloma Bone Disease* and *Understanding Your Blood and Blood Tests.*

Disclaimer

The information in this InfoGuide is not meant to replace the advice of your medical team. They are the best people to ask if you have questions about your individual situation.





Myeloma Canada

Myeloma Canada is a registered non-profit organization created by, and for, people living with multiple myeloma. As the only national organization exclusively devoted to the Canadian myeloma community, Myeloma Canada has been making myeloma matter since its founding in 2005.

Working with leading myeloma researchers and clinicians as well as other cancer organizations and local support groups across Canada, Myeloma Canada seeks to strengthen the voice of the Canadian myeloma community and improve the quality of life of myeloma patients, their caregivers and families through education, awareness, advocacy and research.

Myeloma Canada's goals are to:

- Provide educational resources to patients, families and caregivers
- Increase awareness of the disease and its effects on the lives of patients and families
- Advance clinical research and promote access to new drug trials in Canada
- Facilitate access to new therapies, treatment options and healthcare resources

This InfoGuide is dedicated to help the patients and their families who are living with myeloma understand more about what the kidneys do and what happens when the kidneys are damaged and to understand how myeloma kidney disease is managed.

For more detailed information about myeloma and living with myeloma, you can refer to the *Multiple Myeloma Patient Handbook*. To order your free copy, send an e-mail to contact@myeloma.ca or call (579) 934-3885 or toll free 1-888-798-5771.

This information and other InfoGuides are also available for download at www.myeloma.ca.





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What Do the Kidneys Do?

Most people have two kidneys, one located on either side of the spine, just below the rib cage. Each kidney is about the size of a fist and weighs about 160 grams. Your kidneys are connected to your bladder by tubes called **ureters.**

The kidneys carry out many essential functions, including:

- Filtering the blood to get rid of waste products from the bloodstream
- Keeping the mineral (e.g. sodium and potassium) and water content of the body in a healthy range
- Controlling blood pressure and blood glucose (blood sugar) levels
- Producing a number of essential **hormones**

These functions are described in more detail below.

Waste products

Healthy kidneys filter the blood to:

- Remove waste products and excess fluid from the body
- Return vitamins, amino acids, glucose, hormones and other vital substances back into the bloodstream

Blood enters each kidney through the renal artery and passes through hundreds of thousands of tiny filtering systems called **nephrons (see Figure 1).** Each nephron contains a small cluster of specialized blood vessels called the **glomerulus** through which blood is filtered, and a **tubule** which eventually connects to the bladder.

However, not all components that make up blood can pass through the glomerulus. Small molecules such as water and sodium can, but larger molecules such as proteins generally cannot.

Once filtered by the glomerulus, the remaining fluid passes into the tubule. Each tubule consists of a pipe which functions to process the fluid and produce urine. The tubules reabsorb vital substances back into the bloodstream, including glucose (blood sugar). Any substances and extra water that the body does not need pass out of the tubules into the ureter, then into the bladder to be passed out of the body as urine.

Water and electrolytes

For the cells of the body to work properly, they need a stable balance of electrolytes (salts, such as potassium, calcium and sodium) and water.

The salt and water balance of your body is maintained by a series of hormones acting on the kidneys. These hormones control the amount of urine the kidneys produce and what the kidneys excrete. As a rule, healthy urine is transparent or the colour of pale straw. If you do not drink enough, the colour of the urine will darken because the kidneys are excreting a smaller volume of more concentrated urine. If you drink an excess of fluid to keep the body fluids balanced, the kidneys excrete more urine. In this case, because the urine is highly diluted, it may be colourless.

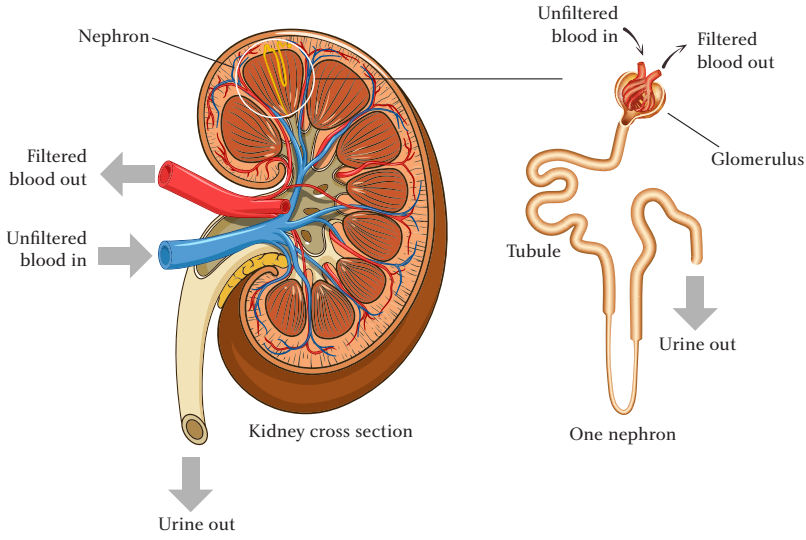
Urine that is a dark brown colour may be a sign of a problem, such as infection in the urinary tract, kidney disease, injury or bleeding disorders. Consult with your healthcare team if this occurs.

Essential hormones

The kidneys also produce hormones and other substances that are needed for other normal body functions. For example:

1) The hormone **erythropoietin,** which is essential for the production of red blood cells in the **bone marrow.** If the kidneys are not working properly they do not produce enough erythropoietin, and this can lead to **anemia.**
2) An active form of **vitamin D,** which helps to regulate the body's calcium levels and therefore promote strong, healthy bones.
3) An enzyme called **renin,** which plays an important role in regulating blood pressure.

Figure 1 – Structure of the kidney



More detail

Kidneys and blood pressure

If the kidneys are not working properly, too much renin can be produced, increasing blood pressure and sometimes resulting in hypertension (high blood pressure). This is one of the reasons why it is common for people with kidney disease to also have high blood pressure.





Myeloma and the Risk of Kidney Disease

People with myeloma are at increased risk of developing kidney disease. At least 20% of people with myeloma have some degree of kidney disease at the time they are diagnosed. Up to 50% develop kidney disease at some point during the course of their myeloma. It is important to understand why myeloma increases the risk of kidney disease and what you can do to reduce your risk.

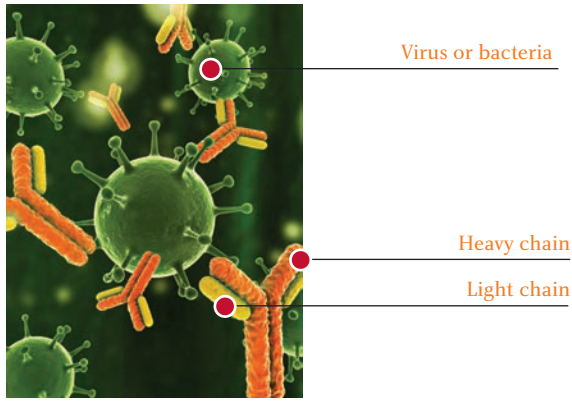
Myeloma kidney disease can occur for a variety of reasons:

- The abnormal protein produced by myeloma cells blocks the tubules
- Other complications of myeloma, such as dehydration or a high calcium level **(hypercalcemia)**
- Some of the drugs used in the treatment of myeloma can cause or contribute to myeloma kidney disease

Light chains and M-protein

In a healthy immune system, there are several different types of **immunoglobulins** (also known as antibodies). Each immunoglobulin is a Y-shaped structure and is always made up of two identical heavy chains and two identical **light chains** (see Figure 2). For more information on the types of antibodies that can be important in different types of myeloma, consult Myeloma Canada's *Multiple Myeloma Patient Handbook*.

Figure 2 – Immunoglobulin structure



A healthy person produces a mixture of the different immunoglobulins, made up of different combinations of heavy and light chains. Each immunoglobulin plays a specialized role in fighting infection.

In myeloma, there is an excess of a single immunoglobulin. This immunoglobulin, called a "monoclonal protein" **(M-protein)** or "paraprotein" is abnormal and interferes with normal blood cell production.

In about 15–20% of patients, the myeloma cells produce only light chains (sometimes called **Bence-Jones protein**) and no whole immunoglobulins. This is called "light chain" or "Bence-Jones" myeloma.

Light chains occur at measurable levels in the bloodstream of most people with myeloma.

Excessive amount of light chains circulating in the bloodstream can damage the kidneys. When they enter the kidneys the light chains are small enough to pass through the glomeruli and into the tubules. In the tubules, they may combine with another protein called the **Tamm-Horsfall protein.** When the light chains bind to the Tamm-Horsfall protein, they produce proteins that are too large to pass into the urine. This can block the tubule and lead to serious kidney damage.

In addition to blocking the tubules, light chains are also directly toxic to the kidney, causing inflammation and leading to further loss of kidney function.

Hypercalcemia

Your bones are constantly being broken down and rebuilt. When old or damaged bone is broken down, the calcium in the bone is released into the bloodstream. Myeloma commonly causes excess bone breakdown and this can cause high levels of calcium in the blood (hypercalcemia). Blood carrying a high concentration of calcium can cause damage as it passes through the kidney.

Hypercalcemia is often found at the time myeloma is diagnosed. Once treatment has started, hypercalcemia is much less common.

More detail

Bone remodelling in myeloma

Two different kinds of cells, found inside the hard tissue of the bone, cooperate to:

- break down old or damaged bone (bone resorption) is the job of **osteoclast** cells
- build up new bone (bone formation) which is carried out by **osteoblast** cells.

In healthy bone, breakdown and build up are balanced. But in myeloma, bone tissue breaks down faster than it can be renewed. On top of this, the osteoclasts produce chemicals that stimulate myeloma cells to grow. This can lead to a vicious cycle which contributes to spreading myeloma. It also leads to bone loss, with fragile bones and risk of fractures, as well as hypercalcemia, which can injure the kidneys.

Keeping myeloma cells under control is the best way to prevent or block this vicious cycle and to preserve normal kidney function.

For more information about hypercalcemia and bone breakdown, consult Myeloma Canada's *Myeloma Bone Disease InfoGuide*.

Dehydration

Dehydration can also aggravate myeloma kidney disease. If fluid intake is not sufficient and dehydration occurs, this can put the kidneys under additional pressure.

For most myeloma patients with any degree of kidney disease at diagnosis, kidney function can be improved by keeping up a high fluid intake. You should try to drink at least 6 to 8 glasses of water per day and limit caffeine intake. However, if you require dialysis, the amount of fluid that you can drink may be restricted.

Self-help

Drink up!

Drinking lots of fluids can help to flush medications and toxins from your body, maintain normal blood volume and pressure, lubricate the joints, limit fatigue and help prevent kidney damage. The best single fluid to drink is water. Unless you are advised otherwise by your healthcare team, try to gradually increase your intake until you are drinking 6 to 8 glasses of water every day.

Try to limit drinks that contain caffeine, such as coffee, tea and soft drinks. Caffeine and alcohol increase your urine output and can lead to dehydration and fatigue.

Medications/myeloma treatments

Certain medications often used in the treatment of myeloma and the management of symptoms and complications may also affect the kidneys, possibly worsening any existing damage. For example, some bisphosphonates – used to treat hypercalcemia or osteoporosis – can be toxic to the kidneys. This is because these drugs are removed from the body through the kidneys, which can put additional strain on them if they are already damaged.

More detail

Changing your bone therapy when you have myeloma kidney disease

Bisphosphonates such as sodium clodronate (Bonefos®), pamidronate (Aredia®) and zoledronic acid (Zometa®) are often used at lower doses in patients with myeloma kidney disease. Ask your doctor if any changes are needed.

Non-steroidal anti-inflammatory drugs (NSAIDs) – such as ibuprofen (Motrin® or Advil®), naproxen (Aleve®) and diclofenac (Voltaren®) – are effective pain-killers, but can be harmful to the kidneys and are not recommended for myeloma patients.

It is important that you inform your doctor about any non-prescription drugs, vitamins or supplements that you may be taking, to ensure that they will not have any negative effects on your kidneys.





What Are the Symptoms of Myeloma Kidney Disease?

When the kidneys are not working properly, harmful toxins and excess fluids build up in the body, which causes symptoms.

The symptoms of myeloma kidney disease may include:

- Thirst
- Fatigue
- Persistent headaches
- Loss of appetite
- Nausea and/or vomiting
- Passing excessive amounts of urine, or very little or no urine
- Swelling in the face and ankles
- Shortness of breath

Many of the symptoms of myeloma kidney disease are quite general and might be confused with symptoms related to other problems, or side effects of myeloma treatments. For example, fatigue can be caused by some myeloma treatments and kidney disease. It is therefore important to mention any new symptoms to your doctor right away.

It is also possible to have no symptoms at all when you develop myeloma kidney disease. This is because the body can tolerate even a large reduction in kidney function before you notice symptoms. For example, most people can remain healthy with only one functioning kidney.

However, as kidney disease is a common complication in myeloma, your kidney function will be checked using regular blood tests, starting at the time of diagnosis (for more, see page 18). This monitoring means that any indication of a kidney problem is usually picked up early.





Tests Used to Detect and Monitor Myeloma Kidney Disease

Laboratory tests are used to tell whether or not you have myeloma and what stage your disease is in. Tests are also needed to keep track of how you are responding to treatment.

Kidney damage can be one of the first signs of myeloma, and your kidney function is likely to improve with effective myeloma treatment. This is why your healthcare team will monitor your kidney function regularly. At the time of diagnosis and afterwards, you will likely be asked for blood and urine samples that provide important clues about the state of your kidneys.

The main test that is performed to diagnose and monitor myeloma kidney disease, and to determine the extent of any damage, is a blood test to measure the level of a molecule called **creatinine.** Creatinine is a waste product that is normally filtered out by the kidney and passed into the urine. A high creatinine level indicates the kidneys are not working normally.

More detail

eGFR and Creatinine

The creatinine level is combined with your age, gender and ethnicity to provide a more accurate measurement of kidney function called an **estimated glomerular filtration rate (eGFR).** The eGFR assesses how well the kidneys are filtering the blood by estimating how many millilitres (ml) of waste fluid your kidneys can filter from the blood in a minute (ml/min). It is possible to calculate an exact value for the GFR, but this requires specialized equipment and is not usually done.

A normal eGFR is 60 ml/min or more. The level at which someone has severe kidney damage – where they may require dialysis – is less than 15 ml/min.

Further elements of your regular blood tests – such as your red and white blood cell levels, free light chain (see page 5) and calcium and electrolyte levels – can also provide an indication of how well your kidneys are working.

Along with the blood samples, laboratory tests on urine are often useful for testing kidney function. In some cases, you may be asked to collect urine over a full day (24 hours).

The kidney biopsy is another test that is used less often but makes possible a definitive diagnosis of kidney disease. A biopsy is a medical procedure, where a small sample of kidney tissue is removed, so the cells can be examined under a microscope for signs of damage.





The Treatment and Management of Myeloma Kidney Disease

There are different ways to treat and manage myeloma kidney disease, depending on its underlying cause. In many cases, myeloma kidney disease can be reversed and in some cases the kidneys can fully recover. Only about 10% of patients will need to have dialysis.

Early diagnosis and intervention is key to preventing permanent kidney damage.

Myeloma treatment and high-dose steroids

The most effective way of treating myeloma kidney disease is to treat the underlying myeloma. Treating the disease will reduce the level of light chain and/or M-protein passing through the kidneys.

If you have kidney damage at diagnosis, you may be given high-dose steroids (usually dexamethasone) as your initial anti-myeloma treatment. In many patients, steroids are effective at rapidly controlling myeloma and reducing light chain levels. Bortezomib is another treatment that is commonly recommended for people with myeloma kidney disease. Bortezomib is usually taken along with a steroid.



Supportive treatment

For the majority of myeloma patients with kidney damage, kidney function will improve by employing measures such as:

Drinking lots of fluids

The most important thing you can do to reduce the risk of myeloma kidney disease developing and limiting any existing damage is to drink plenty of fluids. In many cases, kidney disease can be reversible and a high fluid intake may be enough to reverse the damage.

You should try to drink at least 6 to 8 glasses of water per day. Water is the best fluid to drink. Caffeinated and alcoholic beverages should be limited. Your medical team will give you advice about this.

If you are severely dehydrated you may be given fluid directly into a vein (intravenously). This will correct dehydration quickly. You may require a short stay in hospital if you are treated with intravenous fluids.

If you require dialysis, the amount of fluid you can drink may be restricted. During dialysis, fluid is removed from your blood at each session. If you drink too much water, the dialysis machine will be unable to remove all of the fluid, which can cause problems. The amount of fluid to drink if you are receiving dialysis treatment varies from person to person. Your healthcare team will advise you.

Treating hypercalcemia with bisphosphonates

Bisphosphonates, drugs that help prevent bone breakdown are used in the treatment of myeloma bone disease. With bisphosphonates, less calcium is released from the bones and hypercalcemia may be prevented or resolved.

Self-help

Hold off on calcium supplements

In people without myeloma, calcium supplements are often recommended for bone health. But if you have myeloma, never take a calcium supplement without checking with your doctor. Too much calcium in the blood can be unhealthy.

Bisphosphonates are removed from the body by the kidneys. If you have myeloma kidney disease, doctors will monitor your kidney function more closely if you are receiving bisphosphonate treatment. As explained on page 7, bisphosphonate drugs may need to be used at low doses in some people with myeloma kidney disease.

Rapidly treating kidney infections

A kidney infection can be very painful and unpleasant and usually happens when bacteria travel up from your bladder into one or both of your kidneys. If treated promptly, a kidney infection does not cause serious harm. If a kidney infection is not treated, it can get worse and cause permanent kidney damage.

Avoiding NSAIDs as pain-killers

Avoid using non-steroidal anti-inflammatory drugs (NSAIDs) such as ibuprofen (Motrin® or Advil®), naproxen (Aleve®) and diclofenac (Voltaren®) as pain-killers. These drugs can reduce the flow of blood to the kidneys and contribute to kidney problems.

Erythropoietin

As mentioned previously, the kidneys produce the hormone erythropoietin which causes the bone marrow to produce red blood cells. In people with myeloma kidney disease, the kidneys may not produce enough erythropoietin, and this can lead to anemia.

Long-lasting or severe anemia can be treated with synthetic (man-made) erythropoietin (EPO), a protein that stimulates the body to make more red blood cells. EPO may be called epoetin-alfa (Eprex®) or darbepoetin-alfa (Aranesp®). EPO treatment, given by injection under the skin, may be helpful for maintaining red blood cell levels in myeloma patients with kidney problems.

Allopurinol

As the kidneys are involved in removing waste products from the body, they play an important role in clearing breakdown products of myeloma cells killed by treatment from the body. A potentially serious complication can occur if a large number of myeloma cells is killed rapidly and toxins are released suddenly into the bloodstream. If the kidneys are not working as well as they should, they may not be able to efficiently remove these toxins from the blood. The toxins can then cause a number of kidney-related complications, including possible kidney failure.

People with myeloma kidney disease are at higher risk of these complications because their kidneys are already damaged. In cases where the level of myeloma protein is very high and the disease is progressing rapidly, a drug called allopurinol may be given along with the myeloma treatment to prevent these complications. Allopurinol is usually given for at least for the first few cycles of treatment, when the greatest number of myeloma cells are being killed.

Dialysis

In most patients, kidney damage is temporary and the kidneys can recover. However, in around 10% of patients kidney problems are more severe and require a regular treatment called dialysis.

Dialysis is a form of treatment that replicates many of the kidney's functions. It is often used to treat severe kidney disease, where the kidneys have lost most or all of their function.

There are two types of dialysis: hemodialysis and peritoneal dialysis

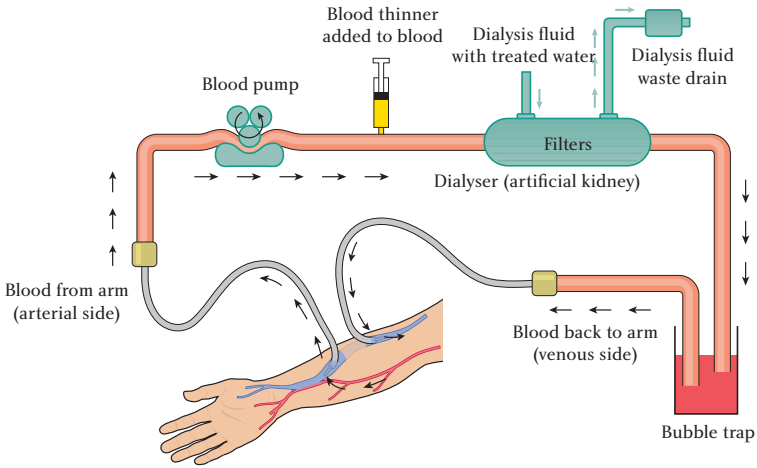
Hemodialysis is used in the early stages of treatment for kidney failure. If kidney function does not recover, hemodialysis or peritoneal dialysis can be used in the long term. Your healthcare team will spend some time going through the choices available to you.

Hemodialysis

If you need hemodialysis for kidney failure, this is usually required quite soon after the damage is first identified (within days or weeks).

Hemodialysis is carried out by inserting a dialysis line (a plastic tube) into a vein in the top of the leg or the neck. This line is then attached to a machine that pumps your blood through a filter. This gets rid of waste products and excess fluids. After the blood has passed through the filter, it is returned to your body **(Figure 3)**. Each hemodialysis treatment takes 4 to 5 hours and is usually required at least three times a week.

Figure 3



Peritoneal dialysis

Peritoneal dialysis is an alternative type of dialysis. It involves using the **peritoneum** as a filter. The peritoneum is a thin membrane (covering) that surrounds and supports the abdominal organs, such as the stomach and liver. Like the kidneys, the peritoneum contains thousands of tiny blood vessels, making it an effective filtering device.

During peritoneal dialysis, a small flexible tube, known as a catheter, is attached to an incision (opening) in your abdomen. A special dialysis fluid is introduced into the space that surrounds your abdominal peritoneum. As blood moves through the peritoneum, waste products and excess fluid are removed from the blood and into the dialysis fluid. The dialysis fluid is then drained from your body. The process of peritoneal dialysis lasts roughly 30 to 40 minutes and is repeated around four times a day. Alternatively, you can run it overnight.

Peritoneal dialysis is not commonly used in myeloma patients. However, your kidney specialists will discuss this with you as an option if your kidneys do not recover and you need long-term dialysis treatment. More about living day-to-day on long-term dialysis can be found on pages 15-16.

Plasmapheresis

Theoretically, the level of light chains can be reduced by physically removing them from the blood. Plasmapheresis (also called plasma exchange) has been used to rapidly decrease the light chain concentrations in myeloma patients with severe kidney damage with varying degrees of success.

A new method of hemodialysis is currently being investigated and early indications suggest that it may be more efficient at removing light chains than either plasmapheresis or conventional dialysis. Studies are currently in progress to see if this new approach improves outcomes for myeloma patients with kidney disease.







Living with Myeloma Kidney Disease

Treating your myeloma, leading a healthy lifestyle and following your healthcare team's advice may help prevent kidney damage from occurring. If kidney damage does occur, it is still possible to reduce your symptoms and prevent further kidney damage. Having kidney disease may seem worrisome for you and your family, but it does not have to take over your life.

Looking after your kidneys

The following steps can help keep your kidneys as healthy as possible:

- Do not smoke
- Maintain a healthy blood pressure that is neither too high nor too low. Talk to your healthcare team about the healthiest range for your blood pressure and consider monitoring it regularly. Eating a healthy, varied diet that is low in salt (sodium), maintaining a healthy weight and doing gentle exercise can help to keep your blood pressure in a healthy range
- Myeloma patients who also have diabetes should make sure their blood sugar levels are kept under control
- Keep well hydrated
- Look out for the symptoms of kidney damage listed on page 8 and report them to your healthcare team as soon as possible

Living on dialysis

If you need dialysis, this can be disruptive to your day-to-day life because of the amount of time it requires.

On average, about half of myeloma patients who require dialysis will recover their kidney function in about three weeks. The other half may need longer-term treatment.

Both hemodialysis and peritoneal dialysis cause side effects. The following section provides information on the most common side effects of hemodialysis (the dialysis method most frequently used in myeloma) and how to manage them.

Side effects of dialysis

Fatigue

Fatigue, where you feel tired and exhausted all the time, is a common side effect of myeloma and some myeloma treatments. But patients who are on hemodialysis on a long-term basis have a particularly high risk of developing fatigue. Fatigue is thought to be caused by a combination of:

- The loss of normal kidney function
- The effects that dialysis can have on the body
- The dietary restrictions associated with dialysis
- Stress and anxiety

There are several treatment options that may be of some use in helping to improve the symptoms of fatigue.

You may want to consult a dietitian to help you adjust your diet in order to boost your energy levels. Moderate, regular exercise can also improve symptoms of fatigue. Although it may be hard even to think about exercise when you are feeling exhausted, just a small increase in physical activity can boost energy levels.

Low blood pressure

Low blood pressure (hypotension) is one of the most common side effects of hemodialysis. It can be caused by the drop in fluid levels that occurs during dialysis. Low blood pressure can cause nausea and dizziness.

The best way to minimize the symptoms of low blood pressure is to ensure you keep to your daily fluid intake recommendations. If symptoms of low blood pressure persist, you should consult your dialysis unit to see if the amount of fluid used during dialysis needs to be adjusted.

Infection

Patients receiving hemodialysis have an increased risk of developing an invasive infection caused by Staphylococcus aureus bacteria.

This type of bacteria is usually responsible for minor skin infections such as boils. However, the hemodialysis process can allow the bacteria to enter the body where they can cause a more serious, invasive infection know as sepsis or blood poisoning. In sepsis, the infection spreads through the blood, leading to multiple organ failure.

The first symptoms of a septic infection include:

- A high temperature (fever) of 38˚C (100.4˚F) or above
- Dizziness, which is related to a decrease in blood pressure, or a worsening of low blood pressure if you already have it

If you have a high temperature, you should contact your dialysis unit immediately for advice. If you develop an invasive infection, you will need to be admitted to hospital and treated with antibiotics.



Muscle cramps

During a hemodialysis session, some people experience muscle cramps, usually in their lower legs. Cramps are thought to be caused by the muscles reacting to the fluid loss that occurs during hemodialysis.

You should consult your dialysis unit if you have muscle cramps that become particularly painful. Medication may be available that can help you to cope better with the symptoms.



Itchy skin

Many people who receive hemodialysis experience itchy skin. This may be caused by a build-up of potassium in the body. Avoiding potassium-rich food (such as bananas, spinach and salmon) can help reduce the frequency and severity of this side effect. Some people find that using moisturizing cream can minimize the discomfort caused by itching.

Remember, if you require dialysis, your local kidney unit will provide you with personalized information and specialist support.



The Future

Myeloma kidney disease is a common complication of myeloma and adds to the overall burden of the disease. If myeloma is diagnosed early, rapid intervention to reduce the level of excessive light chains can, in most cases, successfully prevent or reverse myeloma kidney disease and improve patient outcomes.

A great deal of research is in progress to further understand the most effective ways to help people with long-lasting or permanent myeloma kidney disease.

Alternatives to bisphosphonates (which can be toxic to the kidneys) and advances in dialysis are the subject of a number of clinical trials around the world. For example, a new method of hemodialysis called "extended high cut-off hemodialysis" is being investigated and early indications suggest that it may be more efficient at removing light chains than either plasmapheresis or conventional dialysis.

Ongoing investigations such as this will give doctors a greater understanding of which treatment options will be most effective for myeloma patients with kidney disease.

Self-help

Track your own myeloma and kidney test results

Although it is not necessary, you may wish to track your blood test results, so you can monitor the changes in your blood and kidney function over time. You can use a tracking chart or create your own log in a blank notebook or graph your test results using a spreadsheet.







Questions for your Healthcare Team

Your healthcare team is there to support you, so don't hesitate to ask them questions about your condition and your treatments.

Some questions you may want to ask your doctor or medical team include:

- Are my kidneys affected?
- What is my creatinine level (or eGFR)? How far is that from a level you would like to see?
- How often should I have check-ups and blood tests?
- Will my bisphosphonate dose be reduced or stopped?
- What can I do to help improve my kidney function?
- How much water should I try to drink every day?
- What kind of foods should I eat?
- What range should my blood pressure be in? Should I monitor my blood pressure at home?
- Is it safe for me to exercise? Are there any specific types of exercise that are recommended?
- Will my myeloma treatments help my myeloma kidney disease?
- Will I need to have additional treatment for my myeloma kidney disease?
- Will I need dialysis? What effect is this likely to have on my day-to-day life?



Glossary

Anemia: A decrease in the normal number of red blood cells or hemoglobin level in the blood. Myeloma cells in the bone marrow decrease red cell production, which causes anemia and results in shortness of breath, weakness and tiredness.

Biopsy: A medical procedure in which a small sample of tissue, from the kidney or some other organ, is removed so it can be examined carefully under the microscope.

Bone marrow: The soft, spongy tissue in the centre of bones that produces white blood cells, red blood cells and platelets.

Bone remodelling: A balanced state of bone production and destruction that is found in healthy bone. In some conditions, including myeloma bone disease, this balance is lost, and bone tissue breaks down faster than it can be built up. This can lead to fragile bones and hypercalcemia.

Calcium: A mineral that can be found in the bloodstream, although it is stored mostly in bone tissue. An abnormally high level of calcium in the blood is called hypercalcemia.

Creatinine: A small chemical compound normally excreted by the kidneys. If the kidneys are damaged, the serum level of creatinine builds up, resulting in an elevated serum creatinine. The serum creatinine test is used to measure kidney function. The eGFR, another way of expressing kidney function, is based on serum creatinine and other information about the patient.

Dialysis (also called hemodialysis): When a person's kidneys are unable to filter blood, the blood is cleaned by passing it through a dialysis machine.

Erythropoietin (EPO): A hormone produced in the kidney which is involved in the production of red blood cells. Myeloma patients with damaged kidneys may not produce enough erythropoietin and can become anemic. Injections of synthetic EPO (Epoetin-alfa (Eprex®) or Darbepoetin-alfa (Aranesp®)) are sometimes used to increase the erythropoietin level.

Estimated glomerular filtration rate (eGFR): The volume of fluids filtered by the kidneys

over a period of time. The eGFR is measured by a blood test. Also called creatinine clearance.

Fatigue: Feeling exceptionally tired, lethargic or exhausted all or most of the time.

Glomerulus: One of the key structure of the nephron of the kidney. It is composed of a cluster of small vessels, and acts as a filter to separate waste products from the blood.

Hormone: Chemicals produced by various glands of the body that regulate the actions of other cells or organs.

Hypercalcemia: A higher-than-normal level of calcium in the blood, usually resulting from bone destruction. This condition can cause a number of symptoms, including loss of appetite, nausea, thirst, fatigue, muscle weakness, restlessness and confusion. Hypercalcemia is often associated with reduced kidney function since calcium can be toxic to the kidneys. For this reason, it is usually treated on an emergency basis using intravenous (i.e. into a vein) fluids combined with drugs to reduce bone destruction together with direct treatment for the myeloma.

Immunoglobulins: Proteins found in the blood and produced by specialized white blood cells (plasma cells) to fight infections and disease. Also known as antibodies. Immunoglobulins are made up of two identical heavy chains and two identical light chains to form a Y-shaped structure.

Light chains (also known as Bence-Jones protein): A part of an immunoglobulin (antibody). In humans, there are two type of light chain: kappa and lambda. An excess of light chains is found in the blood of most people with myeloma, including people who produce whole immunoglobulin (M-protein; paraprotein). In about 15 % - 20% of patients, the myeloma cells produce only light chains and no whole (intact) immunoglobulins. This is called light chain or Bence-Jones myeloma.

M-protein: An abnormal immunoglobulin produced by myeloma cells and measured in the blood of myeloma patients. M-protein is sometimes also called paraprotein, monoclonal protein, monoclonal spike (M-spike) or monoclonal peak (M-peak). Measurements of M-protein are used to monitor the activity of myeloma and its response to treatment.

Nephron: One of thousands of tiny structures within each kidney responsible for filtering blood to remove water and waste products. It is made up of a glomerulus, which acts as a filter, which is connected to a drainage tube (tubule).

Osteoblast: A kind of cell found in the bone that produces new, calcium-rich bone tissue.

Osteoclast: A kind of cell found in the bone that removes old bone tissue. Normally osteoclasts and osteoblasts work together, removing and replacing the hard tissue of bones in a single process. If osteoclasts are more active than osteoblasts, there is a net loss of calcium from the bone tissue, which leads to excess calcium in the bloodstream (hypercalcemia).

Peritoneum: A large, thin and complex lining within the abdomen which provides a covering for organs such as the large and small bowel and the stomach. It provides support for these organs.

Renin: An enzyme secreted by and stored in the kidneys that promotes the production of the

protein angiotensin. Renin plays an important role in regulating blood pressure.

Side effect: Problems or undesirable effects that occur due to drugs or procedures used for disease treatment.

Tamm-Horsfall protein: The most abundant protein in normal urine, it is produced by the tubules. Its function is not well understood.

Tubule: A small tube that drains particles and fluid removed from the blood in the nephron by the filters (glomerulus). In the tubule, any substances the body needs can be reabsorbed and wastes are concentrated into urine for excretion.

Ureter: The tube that takes urine from the kidneys to the bladder.

Vitamin D: A nutrient that helps regulate the amount of calcium in the body, promoting healthy bones and teeth. Vitamin D is made by our body in reaction to sunlight. Vitamin D is also found in a small number of foods such as oily fish (e.g. salmon, sardines) and eggs.





Make Myeloma Matter

Every year, Myeloma Canada provides information to thousands of people with myeloma and their families and caregivers, and helps many more by providing programs and services such as the annual Myeloma Canada National Conference, Patient and Family InfoSessions, the Myeloma Matters newsletter and webinars.

That is why we need your help. We depend on support and generous donations from people like you to provide support to myeloma patients, their families and their caregivers. All donations are greatly appreciated and allow us to continue our vital work.

Ways you can help

Donate

You can make your donation online at **www.myeloma.ca**, over the phone by calling toll-free at 1-888-798-5771, or by mailing a cheque payable to Myeloma Canada to:

Myeloma Canada
1255 Trans-Canada Highway
Suite 160
Dorval, QC
H9P 2V4

Fundraise

There are other ways you can support Myeloma Canada, such as taking part in the annual Multiple Myeloma March held in cities across Canada, or by fundraising for Myeloma Canada in your local community. When so much about myeloma is beyond the control of the people that it affects and those who care for them, fundraising can be a rewarding and fun way of doing something positive for yourself and for others affected by myeloma.

Contact the fundraising team at (579) 934-3885 or toll-free at 1-888-798-5771 for more information, or visit **www.myeloma.ca**.



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Myeloma Canada Scientific Advisory Board

Nizar J Bahlis, MD
Tom Baker Cancer Center
Assistant Professor
University of Calgary
Foothills Medical Center
Calgary, AB

Andrew R Belch, MD
Division of Medical Oncology
Department of Oncology
Cross Cancer Institute
University of Alberta
Edmonton, AB

Christine Chen, MD
Assistant Professor
Department of Medical
Oncology and Hematology
Princess Margaret Hospital
University Health Network
Toronto, ON

Jonathan Keats, PhD
Assistant Professor
Integrated Cancer Genomics Division
Translational Genomics
Research Institute
Phoenix, AZ

Richard LeBlanc, MD
Maisonneuve-Rosemont Hospital
Clinical Assistant Professor
of Medicine
University of Montreal
Montreal, QC

Paola Neri, MD, PhD
Clinical Assistant Professor
University of Calgary
Calgary, AB

Linda Pilarski, PhD
Division of Experimental Oncology
Department of Oncology
Cross Cancer Institute
University of Alberta
Edmonton, AB
Member, IMF Scientific Advisory Board

Donna E Reece, MD
Professor of Medicine
Director, Program for Multiple
Myeloma and Related Diseases
Department of Medical
Oncology and Hematology
Princess Margaret Hospital
University Health Network
Toronto, ON
Member, IMF Scientific Advisory Board

Tony Reiman, MD
Medical Oncologist
Saint John Regional Hospital
Assistant Dean of Research Dalhousie
Medicine
New Brunswick
Saint John, NB

Jean Roy, MD
Maisonneuve-Rosemont Hospital
University of Montreal
Montreal, QC

Michael Sebag, MD, PhD
Assistant Professor
McGill University Faculty
of Medicine
McGill University Health Centre
Montreal, QC

Chaim Shustik, MD
Professor of Medicine & Oncology
McGill University Faculty
of Medicine
Royal Victoria Hospital
Montreal, QC
Member, IMF Scientific Advisory Board

Kevin J Song, MD
BC Cancer Research Centre
Vancouver General Hospital
Vancouver, BC

Rodger Tiedemann, PhD, ChB, MB
Scientist, Ontario Cancer Institute
Staff Hematologist
Division of Medical Oncology &
Hematology
Princess Margaret Hospital
Assistant Professor
of Medicine
University of Toronto
Toronto, ON

Suzanne Trudel, MD
Associate Professor
Clinician/Research Scientist
Department of Medical Oncology and
Hematology
Princess Margaret Hospital
University Health Network
Toronto, ON

Darrell White, MD
Nova Scotia Cancer Centre
Queen Elizabeth II Health
Services Centre
Dalhousie University
Halifax, NS

MYELOMA CANADA
RESEARCH NETWORK

MAKING MYELOMA MATTER

The mission of the Myeloma Canada Research Network is to conduct clinical and translational research in a collaborative manner to improve patient outcomes in multiple myeloma, and to provide scientifically valid and peer-reviewed consensus opinions on the diagnosis and treatment of multiple myeloma.

Myeloma Canada

Mailing Address:

Myeloma Canada
1255 Trans-Canada Highway
Suite 160
Dorval, QC
H9P 2V4

Telephone:

Toll-free: 1-888-798-5771

E-mail:

contact@myeloma.ca

Website:

www.myeloma.ca

International Myeloma Foundation

Mailing Address:

International Myeloma Foundation
12650 Riverside Drive, Suite 206
North Hollywood, CA
91607-3421
USA

Hotline:

1-800-452-CURE (2873)

Telephone:

(818) 487-7455

E-mail :

TheIMF@myeloma.org

Website:

www.myeloma.org

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