MyelomaUK

Myeloma and the kidney

Symptoms and complications Infoguide

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You will find a definition of the terms highlighted in **bold** throughout this publication in the 'Medical terms explained' section on page 23.

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

This publication is intended for a UK audience. It therefore may not provide relevant or accurate information for a non-UK setting.

Myeloma – an overview

This section explains some key facts about myeloma, including what it is, how it affects patients, and how it is treated. If you are newly diagnosed this section can be a good place to start. If you have been living with myeloma for some time, this information might be familiar, but it can still be a useful reminder before reading about specific aspects of myeloma.

Myeloma is a type of cancer arising from **plasma cells** that are normally found in the **bone marrow**. Plasma cells are a type of **white blood cell** which form part of the **immune system**.

Normal plasma cells produce different types of **antibodies** to help fight infection. In myeloma, some of the plasma cells become cancerous (sometimes called **malignant**) and usually release a large amount of a single type of antibody, known as **paraprotein**, which has no useful function. Myeloma is often diagnosed and monitored by measuring this paraprotein. The cancerous plasma cells are often called **myeloma cells**.

Sometimes, myeloma cells produce only part of the paraprotein, known as **light chains**. These also have no useful function. In other types of myeloma, the myeloma cells only produce small amounts of paraprotein or no paraprotein at all. There are other ways to diagnose and monitor these types of myeloma.

Myeloma affects multiple places in the body where bone marrow is normally active, such as the bones of the spine, pelvis, rib cage and the areas around the shoulders and hips. This is why it is sometimes referred to as 'multiple myeloma'.

Most of the complications and symptoms of myeloma are caused by a buildup of the cancerous myeloma cells in the bone marrow and the presence of paraprotein or light chains in the body.

Common problems in myeloma include bone pain, bone fractures, **fatigue**, frequent infections and kidney damage.

Myeloma is highly treatable in most cases. Treatment is aimed at controlling the disease, relieving

the complications and symptoms it causes, and extending and improving the **quality of life**. Treatment for myeloma is often most effective when two or more treatments, with different ways of working, are given together.

Myeloma is known as a relapsing and remitting cancer: patients are treated and generally go into **remissions** when their cancer is not active and often is not being treated, followed by **relapses** when the myeloma is active and needs treatment again. Remissions can last for long periods of time, and many patients have a number of remissions and relapses during their lifetime. Although myeloma is not currently curable, the outlook for patients has improved greatly over recent years and is continuing to improve. There are many different treatments available, and others are being developed in clinical trials.

The causes of myeloma are not fully understood but it is believed to be caused by an interaction of both genetic and environmental factors.

Key facts

- On average 6,200 people are diagnosed with myeloma every year in the UK
- There are over 33,000 myeloma patients in the UK
- Myeloma is the third most common type of blood cancer, and accounts for 1 in 50 of all new cancer cases diagnosed each year
- Although more common in older people, around 1 in 4 myeloma patients are diagnosed under the age of 65

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 salt (such as sodium and potassium) and water content of the body within normal range
- Controlling blood pressure
- 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 thousands of tiny filtering systems called **nephrons** (see Figure 1 on page 5). Each nephron contains a small cluster of specialised blood vessels called the **glomerulus** and a **tubule** which eventually connects to the bladder. Blood is passed through the glomerulus, which acts as a filter. 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 protein cannot.

Once filtered by the glomerulus, the fluid passes into the tubule. Each tubule consists of a pipe which reabsorbs useful substances present in the filtered fluid back into the bloodstream. Any substances and extra water that the body does not need pass out of the tubules and into the bladder to be removed from the body as urine.

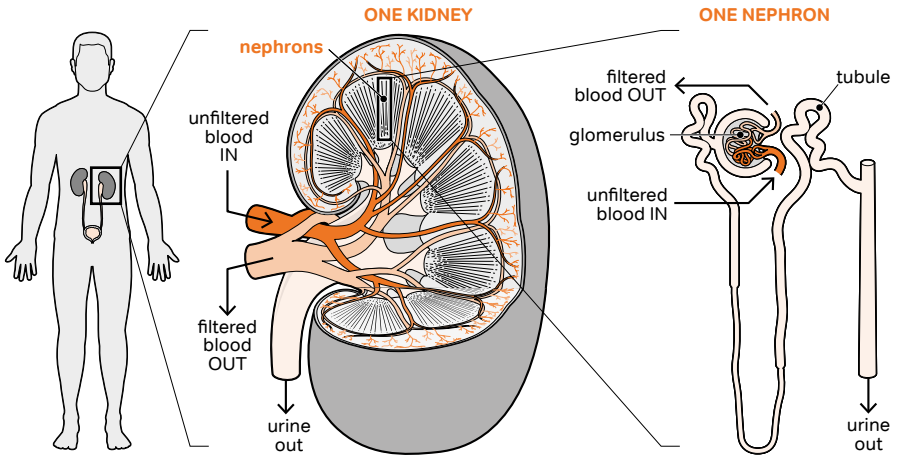

Figure 1. Structure of the kidney and structure of the nephrons which filter blood

Water and salts

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

The salt and water balance of your body is important for several vital bodily functions including sending messages to and from the brain.

The balance of salt and water is maintained by a series of hormones acting on the kidneys.

These hormones control the amount of urine that the kidneys produce and what the kidneys excrete.

For example, if you do not drink enough water, your body fluids become more concentrated and your kidneys produce less urine (which is also more concentrated). On the other hand, if you drink too much water, your body fluids become more diluted and your kidneys produce more urine (which is also more diluted) to get rid of the extra fluid.

Essential hormones

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

- 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, which can lead to **anaemia.**
- An active form of **vitamin D**, which helps to regulate the body's calcium levels and therefore promote strong, healthy bones
- An enzyme called **renin** which plays an important role in regulating blood pressure. If the kidneys aren't working properly, too much renin can be produced, increasing blood pressure and sometimes resulting in high blood pressure (known as hypertension). This is one of the reasons why it is common for people with kidney disease to also have hypertension.

Why does myeloma cause kidney disease?

Myeloma kidney disease is a common complication of myeloma. Up to a half of all patients will have some degree of kidney disease at diagnosis and more will develop it at some point during the course of their myeloma.

Myeloma kidney disease can occur for a variety of reasons. The abnormal protein produced by myeloma cells can damage the kidneys by blocking the tubules. Other complications of myeloma, such as dehydration and a high calcium level (hypercalcaemia), as well as some of the drugs used to treat myeloma, can also cause or contribute to myeloma kidney disease.

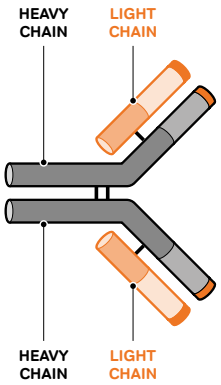

Figure 2. Structure of an antibody including two heavy chains and two light chains

Light chains and paraprotein

In a healthy immune system, there are several different types of immunoglobulin (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).

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

In myeloma, however, a large amount of a single type of immunoglobulin (called paraprotein) is produced. Paraprotein plays no useful role in the body.

In around 1 in 5 patients, the myeloma cells produce only light chains and no whole immunoglobulins (paraprotein) at all. These are called **free light chains** (sometimes called **Bence Jones proteins** when they are in the urine). This type of myeloma is called **light chain myeloma**.

Light chains are also elevated and measurable in the vast majority of myeloma patients who produce whole immunoglobulins (paraprotein).

The light chains circulating in the bloodstream in myeloma can damage the kidneys. When they enter the kidney, they are small enough to pass through the glomeruli and into the tubules. In the tubules, they can combine with other proteins which together produce big proteins that stick in and block the tubule rather than passing through into the urine. This can cause kidney damage.

In addition to physically blocking the tubules, light chains are also directly toxic to the kidney, causing inflammation to the kidney tissues and increasing any damage.

Hypercalcaemia

Bone is high in calcium and as it is broken down, calcium is released into the blood. Myeloma commonly causes excess bone breakdown and this can cause high calcium levels in the blood (known as **hypercalcaemia**).

Hypercalcaemia is most often present at the time of diagnosis and is much less common once treatment has started. High levels of calcium in the blood passing through the kidneys can damage them.

Infection

Myeloma itself and some of its treatments can affect how well your immune system works, leaving you at higher risk of infection. Kidney infections can, if not treated promptly, worsen kidney function, and sometimes cause permanent damage.

Dehydration

Dehydration can make myeloma kidney disease worse by putting the kidneys under additional pressure.

For the majority of myeloma patients with any degree of kidney disease at diagnosis, kidney function can be improved by keeping up a high fluid intake. Unless you have been advised otherwise, you should try to drink at least 2 litres (3–4 pints) of fluids per day (see page 12). However, if you require **dialysis**, you are likely to have to limit your fluid intake. Your healthcare team will always advise you if this is the case.

Drugs used in myeloma

Certain drugs used to treat myeloma and its complications may also affect the kidneys, worsening any existing damage.

For example, some **bisphosphonates** used to treat myeloma bone disease can be toxic to the kidneys. This is because these medicines are removed from the body via the kidneys, so they can put additional strain on the kidneys if they are already damaged. This includes **zoledronic acid (Zometa®)** and **pamidronate disodium**.

Because of this, bisphosphonates are used with caution in patients with myeloma kidney disease. They are often given at lower doses or are temporarily stopped if kidney function worsens.

Non-steroidal anti-inflammatory drugs (NSAIDs) such as ibuprofen, diclofenac and high-dose aspirin (300 mg), can be toxic to the kidneys and are therefore not recommended for myeloma patients.

⚠ **Supplements or herbal medicines that have not been prescribed by your haematologist may cause harm when taken alongside your prescribed treatment.**

You must speak to your healthcare team before taking any kind of supplement or alternative treatment, including herbal, traditional or natural medicines and remedies, and vitamins or wellbeing supplements, to ensure it is safe to do so.

What are the symptoms of myeloma kidney disease?

When the kidneys are not working properly, other parts of the body can be affected in a variety of ways. This can cause a range of 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 feet, ankles or hands

Shortness of breath

Many of the symptoms of myeloma kidney disease are quite general and can have other causes. For example, some of the symptoms are also common **side effects** of myeloma treatments (such as fatigue and nausea).

It is therefore important to mention any new symptoms to your healthcare team straight away so the correct cause, or causes, can be identified.

Patients with myeloma kidney disease may have no symptoms. This is because the body can tolerate even a large reduction in kidney function. 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 monitored through regular blood tests (more on page 11). This will allow any kidney problems to be picked up early.

Tests used to detect and monitor myeloma kidney disease

Myeloma kidney disease can be detected, diagnosed and monitored through regular blood tests.

Regular blood chemistry tests will 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. High creatinine levels in the blood can indicate that the kidneys are not working normally.

The creatinine level is combined with your age, gender and ethnicity to provide a more accurate measurement of kidney function. This is 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).

A normal eGFR is 90 ml/min or more. An eGFR of less than 30 ml/min indicates severe kidney damage, and if it is less than 15 ml/min you may need to have dialysis.

Other blood tests you will have regularly – such as those measuring your red and white blood cell counts and calcium levels – can also indicate how well your kidneys are working.

Further tests which can provide important information about your kidneys include:

- Urine tests – used to see whether there is blood or protein in your urine. The results of some urine tests can be given immediately, but other tests have to be sent to a laboratory for analysis
- Kidney biopsy – a definite diagnosis of kidney disease may be made by taking a small sample of kidney tissue so the cells can be examined under a microscope for damage. This test is only occasionally done in myeloma patients

For more information see the **Tests and Investigations Infoguide** from Myeloma UK

Treatment and management of myeloma kidney disease

There are different ways to treat and manage myeloma kidney disease, depending on the underlying cause of the kidney damage.

It is possible for myeloma kidney disease to be reversed through treatment, and in some cases the kidneys can fully recover. However, in about 1 in 10 of patients, dialysis is needed.

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

Treating the underlying myeloma

The most effective way to treat myeloma kidney disease is to treat the underlying myeloma and in doing so, reduce the light chain and paraprotein level.

If you have kidney damage at diagnosis, you may be given high-dose steroids (such as dexamethasone) before you are started on anti-myeloma treatment. This is because high-dose steroids have been shown to be effective at rapidly reducing light chain levels in many patients.

Supportive treatment

For the majority of myeloma patients with kidney damage, kidney function will improve when measures such as the following are taken:

Drinking lots of fluids

The most important thing you can do to both reduce the risk of myeloma kidney disease developing, and improve any existing damage, is to drink plenty of fluids.

Unless you have been advised to restrict your fluid intake, you should try to drink at least 2 litres (3–4 pints) of fluids per day. Most liquids count, including water, sparkling water, juice, squash, decaf tea and milk. Caffeinated tea, coffee and alcohol can be included, but in moderation. Speak to your healthcare team for specific advice on fluid intake.

If you are severely dehydrated, you may be given fluids directly into a vein, normally in the arm. This will

correct dehydration quickly. You may need a short stay in hospital in this case.

If you require dialysis, however, the amount of fluid you can drink may be restricted. This is because during dialysis, fluid is removed from your blood at each session. If you drink more than the specified amount, the dialysis machine will be unable to remove all of the fluid which can cause problems. The amount of fluid that you can drink if you are receiving dialysis treatment varies from person to person, so you will be given advice by your healthcare team.

Treating hypercalcaemia with bisphosphonates

In myeloma, the breakdown of bone is usually increased and calcium in the bones is released into the blood. Too much calcium in the blood (known as hypercalcaemia) can damage the kidneys.

Bisphosphonates are a type of medicine that work by slowing down and preventing the breakdown of bone. This reduces the amount of calcium released into the blood.

Bisphosphonates are removed from the body via the kidneys. If you have myeloma kidney disease and are receiving bisphosphonate treatment, your doctors will therefore monitor your kidney function more closely. A reduced dose of bisphosphonate treatment may be used, or bisphosphonate treatment may be temporarily withdrawn, in some circumstances.

Rapidly treating kidney infections

A kidney infection usually happens when bacteria travel up from your bladder into one or both of your kidneys. The signs and symptoms of a kidney infection include:

- Fever (temperature above 37.5°C)
- A temperature below 36°C
- Chills and sweating
- Burning sensation or pain when passing urine, or a frequent need to urinate
- Nausea and/or vomiting
- Pain in the abdomen

If treated promptly, a kidney infection is not likely to cause serious harm but it might make you feel very unwell. If a kidney infection is not treated, it can get worse and cause permanent kidney damage.

For more information, see the **Infection and myeloma Infosheet** from Myeloma UK

Avoiding NSAIDs as painkillers

NSAID-type painkillers (see page 9) are not recommended for myeloma patients because they are toxic to the kidneys. The drugs which should be avoided include:

- High-dose aspirin (usually 300 mg)
- Ibuprofen
- Diclofenac

Low-dose aspirin (usually 75mg) is sometimes prescribed in myeloma as it can help prevent blood clots.

Your medical team will also avoid other treatments that can make kidney problems worse. Some drugs can be given safely if you have kidney disease, but are given at a lower dose, because your kidneys cannot remove them from your body as quickly as normal.

Erythropoietin (EPO)

The kidneys produce a hormone called erythropoietin which is required for the production of red blood cells in the bone marrow.

If you have myeloma kidney disease, your kidneys may not produce enough erythropoietin, which can lead to anaemia.

Chronic or severe anaemia can be treated with a drug called EPO, a synthetic (man-made) version of the erythropoietin hormone. EPO is given by injection under the skin. It is particularly helpful for myeloma patients with kidney problems to help maintain red blood cell levels.

Allopurinol

The kidneys are involved in removing waste products from the body. This includes clearing from the body the remains of myeloma cells that have been killed by treatment. One of these waste products is called uric acid, which is released

into the blood when myeloma cells are broken down. If the kidneys are not working as well as they should, they cannot efficiently remove uric acid which leads to it building up in blood. This can can cause further damage the kidneys.

Patients with myeloma kidney disease are at higher risk of these complications occurring, due to the damage already present. All patients who are receiving chemotherapy-based treatment are given a drug called allopurinol to help prevent these complications, at least for the first few cycles of treatment (when the most myeloma cell death occurs).

Dialysis

In the majority of patients, kidney damage is temporary and the kidneys can recover. However, in up to 1 in 10 patients, kidney problems are more severe and they may need a treatment called dialysis, for a short or longer period.

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 normal function.

There are two types of dialysis, haemodialysis and peritoneal dialysis.

Haemodialysis is used in the early stages of treatment for kidney failure in myeloma patients. If kidney function does not recover then haemodialysis or peritoneal dialysis can be used in the long-term. Your local kidney unit will spend some time going through the choices available to you. Haemodialysis is used more commonly than peritoneal dialysis in myeloma patients with kidney disease.

Haemodialysis

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

During haemodialysis, a plastic tube is inserted into a vein in the top of your leg or 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.

Each dialysis treatment takes up to four hours, and haemodialysis usually needs to be done at least three times a week.

Peritoneal dialysis

Peritoneal dialysis is an alternative type of dialysis. It involves using a part of the body called 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 opening made in your abdomen (tummy). A special dialysis fluid is introduced into the space that surrounds your peritoneum.

As blood moves through the peritoneum, waste products and excess fluid are moved out of the blood and into the dialysis fluid. The dialysis fluid is then drained from your body.

Peritoneal dialysis can be done at home. Each dialysis lasts roughly 30 to 40 minutes and it is repeated around four times a day. Alternatively, you can sometimes run it overnight.

Your healthcare team will discuss this option with you if you need long-term dialysis treatment. More information on living day to day on long-term dialysis can be found on page 17.

Living with myeloma kidney disease

Managing kidney disease in addition to your myeloma may bring additional challenges to day-to-day life. However, there are a number of things you can do to help look after your kidneys.

There are things you can do to help keep your kidneys as healthy as possible and help avoid further damage if you already have kidney disease. If you are having dialysis, you will be given specific advice about diet and fluid intake, and about managing side effects.

Looking after your kidneys

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

- Do not smoke
- Eat a varied diet (particularly avoiding added salt) and do regular gentle exercise. These steps will help you to keep a healthy blood pressure
- Reduce the amount of saturated fat in your diet. Saturated fat can lead to high cholesterol levels, which can increase blood pressure and worsen kidney problems
- Myeloma patients who also have diabetes should make sure their blood sugar levels are kept under control
- Drink plenty of fluids (see page 12)
- Avoid taking NSAID-type painkillers (see page 9)
- Be aware of the symptoms of kidney infection and report them to your healthcare team as soon as possible (see page 13)
- Look out for any signs or symptoms of kidney damage and report them to your healthcare team as soon as possible (see page 10)

Being on dialysis

If you need dialysis, you may find the time required for dialysis disruptive to your day-to-day life.

The length of time you are on dialysis will depend on how severe the damage to your kidneys is.

In myeloma patients who eventually recover kidney function, the average time on dialysis treatment is around 3 weeks. However, around half of myeloma patients who require dialysis will need long-term treatment, remaining on dialysis for the rest of their lives.

Diet restrictions on dialysis

While you are on dialysis, you may be asked to follow a specific diet. In general, dialysis patients are advised to avoid excess sodium as this can contribute to high blood pressure. This means using less salt in cooking and on food, as well as eating fewer salty foods (such as crisps, salted nuts etc).

Patients with kidney disease may have high levels of potassium in the blood, which can interfere with the normal functioning of the body. If you have high levels of potassium, you will be advised to avoid eating too many potassium-rich foods. For example, patients on a low potassium diet might be advised to eat no more than the recommended five fruit and vegetables per day.

Some simple tips to reduce salt and potassium in your diet include the following:

- Use herbs and spices in cooking in place of salt
- Read food nutritional labels carefully
- Avoid salt substitutes (e.g. Losalt®) – these are often made from potassium
- If eating out, ask for sauce and salad dressings on the side – these can be high in salt and should be eaten in small quantities only

Depending on the stage of kidney disease, you may need to make further changes to your diet. Your healthcare team will give you more detailed information on diet while on dialysis.

While you are on dialysis, the amount of fluids you can drink will also be restricted (see page 13). Your healthcare team will advise you.

Side effects of dialysis

Haemodialysis and peritoneal dialysis both cause side effects. This is due to the way that dialysis is carried out and the fact that dialysis can only compensate for the loss of kidney function to a certain extent.

This section provides information on the most common side effects of haemodialysis (the most frequently used dialysis method in myeloma kidney disease) and how to manage them.

Fatigue

Fatigue, where you feel extreme tiredness or exhaustion most or all of the time, is a common side effect in patients who are on haemodialysis or peritoneal dialysis on a long-term basis. It may be caused by:

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

Fatigue may be a particular problem for myeloma patients on dialysis, as it is already a common symptom of myeloma and a side effect of some anti-myeloma treatments.

You may want to consult a dietician if you need to 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 so exhausted, just a small increase in physical activity can boost energy levels.

For more information see the **Fatigue Infoguide** from Myeloma UK

Low blood pressure

Low blood pressure (hypotension) is one of the most common side effects of haemodialysis. 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 minimise the symptoms of low blood pressure is to ensure that you keep to your daily fluid intake recommendations (see page 13). If your symptoms

persist, you should discuss this with your dialysis unit because the amount of fluid used during dialysis may need to be adjusted.

Infection and sepsis

Haemodialysis patients have an increased risk of developing **sepsis**.

Sepsis is a life-threatening complication of an infection. It develops when bacteria enter the body and spread through the blood, potentially leading to multiple organ failure. Sepsis is sometimes referred to as septicaemia or blood poisoning.

Warning symptoms of sepsis can include:

- A high temperature (fever) of 37.5°C or above
- Extreme shivering or muscle pain
- Feeling extremely unwell
- Breathing very fast or feeling breathless
- Slurred speech or confusion

If you think you might be developing sepsis, seek urgent medical help.

Muscle cramps

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

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

Itchy skin

Many patients who receive haemodialysis experience itchy skin. This is thought to be due to a buildup of minerals in the body between dialysis sessions. Tell your healthcare team if your skin becomes itchy. They may recommend creams to soothe and moisturise your skin.

Remember, if you require dialysis your local kidney unit will provide you with a lot of information and specialist support tailored to you.

Future directions

Many people with myeloma will experience kidney disease at some point during the course of their myeloma. Ongoing research into new treatments aims to improve the lives of patients with myeloma, including those with kidney disease.

Provided patients are diagnosed early, rapid intervention to reduce the level of excessive light chains can, in most cases, successfully reverse myeloma kidney disease and maintain kidney function.

In a large scale study looking at patients with varying amounts of kidney disease at diagnosis (excluding very severe), only a small proportion of them had worsened kidney function a year after diagnosis.

The outcomes for patients with myeloma kidney disease have improved a great deal over the years, with myeloma treatments that rapidly reduce paraprotein and light chain levels. Current and planned clinical trials are looking at the safety and effectiveness of different myeloma treatments specifically in patients with kidney disease.

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

Early diagnosis of myeloma is crucial, and can be difficult because the early symptoms of myeloma (and of myeloma kidney disease) are quite vague. Myeloma UK is dedicated to tackling the barriers to early diagnosis, which in turn will reduce the number of patients who develop kidney disease before they start myeloma treatment.

Questions for your healthcare team

It can be helpful to write your questions down and give a copy to your doctor at the start of your consultation. You might want to carry a piece of paper with you so you can make a note of questions as they occur to you.

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

- Are my kidneys affected?
- What is my creatinine level?
- 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?
- Will my anti-myeloma treatment 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?

The **Patient Diary** provides space for you to make a note of any questions you have for your healthcare team. Order your free copy from Myeloma UK at **myeloma.org.uk/publications**

Medical terms explained

Anaemia: A condition in which the amount of haemoglobin in the blood or the number of red blood cells is below the normal levels, causing shortness of breath, weakness and tiredness.

Antibodies (immunoglobulins): Proteins found in the blood produced by cells of the immune system, called plasma cells. Their function is to bind to substances in the body that are recognised as foreign, such as bacteria and viruses, enabling other cells of the immune system to destroy and remove them.

Bence Jones proteins: Free light chains that have been filtered from the blood by the kidneys and are found in the urine. The presence of any Bence Jones protein in urine is abnormal.

Bisphosphonate: A type of medicine that slows down or prevents bone damage. They are given orally or as an intravenous infusion.

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

Dialysis: A procedure which removes waste products from the blood, performed when a patient's kidneys have stopped working.

Erythropoietin (EPO): A hormone produced by the kidneys, which is involved in the production of red blood cells. Injections of synthetic EPO can be given to patients who are anaemic.

Estimated glomerular filtration rate (eGFR): A measure of how well the kidneys are working. It calculates how many millilitres of waste your kidneys are able to filter in a minute.

Fatigue: A feeling of being exceptionally tired, lethargic or exhausted all or most of the time. It does not result from activity or exertion and is not fully relieved by rest or sleep.

Free light chain: A light chain (part of an antibody or immunoglobulin) that is not attached to the rest of the antibody.

Glomerulus: The part of the kidney that is responsible for filtering the blood.

Hormone: A chemical messenger released by a cell or organ in one part of the body that affects another part of the body.

Hypercalcaemia: A higher than normal level of calcium in the blood, which may cause loss of appetite, nausea, thirst, fatigue, muscle weakness, restlessness and confusion.

Immune system: The complex group of cells, tissues and proteins (including antibodies), that protect the body against infection and disease.

Light chains: Part of an antibody (or immunoglobulin). An antibody is made up of two heavy chains and two light chains. There are two types of light chain, kappa and lambda.

Light chain myeloma: A type of myeloma where only the light chain portion of the immunoglobulin is produced.

Malignant: Cancerous cells which have the ability to spread.

Myeloma cells: The abnormal plasma cells that occur in myeloma.

Nephron: One of thousands of tiny structures within the kidney that remove waste from the blood to produce urine.

Non-steroidal anti-inflammatory drug (NSAID): A type of medicine used to prevent or treat pain or inflammation, which do not contain steroids. Examples are ibuprofen and diclofenac. NSAIDs should not be used in myeloma because they can worsen kidney damage.

Pamidronate disodium: A bisphosphonate medicine which is given by intravenous infusion.

Paraprotein: An abnormal antibody (immunoglobulin) produced in myeloma. Measurements of paraprotein in the blood can be used to diagnose and monitor the disease. Also known as M protein.

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

Plasma cells: A type of white blood cell that produces antibodies (immunoglobulins) to fight infection.

Quality of life: A term that refers to a person's level of comfort, enjoyment, and ability to do daily activities. It is a measure of an overall sense of wellbeing.

Red blood cells: A type of blood cell which transports oxygen around the body.

Relapse: The point where disease returns or becomes more active after a period of remission or plateau.

Remission: The period following treatment when myeloma cells and paraprotein are no longer detectable, and there are no clinical symptoms of myeloma.

Renin: An enzyme secreted by and stored in the kidneys. It plays an important role in regulating blood pressure.

Sepsis: A life-threatening complication of an infection when your immune system overreacts to the infection and starts to damage your own tissues and organs. Sometimes called septicaemia or blood poisoning.

Side effects: The undesired effects caused by a medicine or treatment, for example fatigue or nausea.

Tubule: Small tube found in the kidney which reabsorbs salts, minerals and sugars back into the blood.

Vitamin D: A molecule which 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, including oily fish (such as salmon, sardines) and eggs.

White blood cells: A type of blood cell involved in the body's immune system, which help to fight infection and disease.

Zoledronic acid (Zometa®): A bisphosphonate medicine which is given by intravenous infusion.

Useful organisations

Carers UK carersuk.org
0808 808 7777
Provides advice, information and support for carers.

Citizens Advice citizensadvice.org.uk
adviceni.net
England: **0800 144 8848** Wales: **0800 702 2020**
Scotland: **0800 028 1456** Northern Ireland: **0800 915 4604**
Offers advice about debt and consumer issues, benefits, housing, legal matters and employment.

Macmillan Cancer Support macmillan.org.uk
0808 808 0000
Provides emotional, practical, physical and financial information and support to all cancer patients and their carers.

Maggie's maggies.org
0300 123 1801
Provides free practical, emotional and social support to people with cancer and their family and friends.

Mind mind.org.uk
0300 123 3393
Provides advice and support for anyone needing support with their mental health.

NHS 111 Service nhs.uk/111
111
Call 111 when you need medical advice quickly but it's not a 999 emergency. NHS 111 is available 24 hours a day, 365 days a year.

Samaritans samaritans.org
116 123
Listening and support free, 24 hours a day, to anyone who's struggling to cope.

We're here for everything a diagnosis of myeloma brings

Visit **myeloma.org.uk**, a one-stop-shop for information on myeloma; with videos, news and articles to help you keep up to date and live well with myeloma.

Call our **Myeloma Infoline** on **0800 980 3332** for practical advice, emotional support and a listening ear.

Get answers to your questions by emailing our Myeloma Information Specialists at **AskTheNurse@myeloma.org.uk**

Order or download our **information booklets**, which cover all aspects of myeloma – call **0800 980 3332** or visit **myeloma.org.uk/publications**

Learn about myeloma from experts and meet other patients at our **Infodays** and **Digital Infoday Sessions**.

Join a **Myeloma Support Group** to meet other people living with myeloma face to face or online.

Get matched up with a trained **Peer Buddy** for one-to-one support from someone with direct experience of myeloma.

Chat and share experiences with others affected by myeloma, including our peer volunteers, on the **Discussion Forum**.

MyelomaUK

We are Myeloma UK

Myeloma UK is the only UK charity focused on myeloma and its related conditions. We are here for everyone affected by myeloma. Together we make it possible to live longer and better lives with myeloma. Together, we support, so no-one faces myeloma alone.

All our charitable activity is funded by fundraising, voluntary donations, and gifts in wills. We couldn't do it without you, our supporters. Together, we are the cure.

Make a donation

You can donate online at **myeloma.org.uk/donate**, by phone, or by posting a cheque payable to **Myeloma UK**.

Fundraise

Fundraising is a positive way of making a difference. Whether taking part in or holding your own event it raises vital funds and helps raise awareness.

Leave a gift in your will

Over a third of all our charitable activities are funded by gifts in wills. That's a third of Infoline calls, a third of treatment approval panels and a third of research projects.

However you decide to raise funds, our team is here to support you.
Contact us on **0131 230 0429** or email **SupporterCare@myeloma.org.uk**

Nobody ever forgets the moment they are diagnosed with myeloma. Myeloma UK advances the discovery of effective treatments, with the aim of finding a cure. That is what patients want, it's what they deserve and it's what we do.

Judy Dewinter – President, Myeloma UK

We appreciate your feedback. Please fill in a short online survey about our patient information at **myeloma.org.uk/pifeedback** or email any comments to **patientinfo@myeloma.org.uk**

For a list of references used to develop our resources, visit **myeloma.org.uk/references**

Symptoms and complications Infoguide:
Myeloma and the kidney

MyelomaUK

We're here for everything a diagnosis of myeloma brings

Get in touch to find out more about how we can support you

Call the Myeloma Infoline on
0800 980 3332

Email Ask the Nurse at
AskTheNurse@myeloma.org.uk

Visit our website at
myeloma.org.uk

Trusted Information Creator
Patient Information Forum

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Registered Charity No: SC026116

Published by:	Myeloma UK
Publication date:	October 2013
Last updated:	March 2025
Review date:	March 2028