

# Myeloma and the kidney

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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 medical 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

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**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, the plasma cells become cancerous (sometimes called **malignant**) and release a large amount of a single type of antibody, known as **paraprotein**, which has no useful function. It is often through the measurement of paraprotein that myeloma is diagnosed and monitored.

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

Most of the complications and symptoms of myeloma are caused by a build-up of the abnormal plasma cells (often called myeloma cells) in the bone marrow and the presence of paraprotein in the body.

Common problems in myeloma include bone pain, bone fractures, fatigue, frequent or recurrent infection and kidney damage.

Myeloma is highly treatable in the majority of 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 drugs, with different but complementary mechanisms of action, are given together. Treatment is usually given over a number of weeks which may or may not be followed by a rest period. This pattern constitutes one cycle of treatment and a series of treatment cycles is referred to as a course or line of treatment.

While there are many effective treatments for myeloma, unfortunately it is currently incurable. This means that even after successful treatment has

provided a period of **remission** or stable disease, the myeloma will return. This is called a **relapse**.

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

- There are approximately 5,800 people diagnosed with myeloma every year in the UK
- There are over 24,000 people living with myeloma in the UK at any one time
- Myeloma accounts for 15% of blood cancers and 2% of cancers generally
- Myeloma mostly affects people aged 65 and over but it has been diagnosed in people much younger

# What do the kidneys do?

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**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 (e.g. sodium and potassium) and water content of the body constant
- 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). 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 remaining 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.

## Water and electrolytes

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, the body fluids become more concentrated and the kidneys excrete less (and more concentrated) urine. If you drink an excess of fluid, the body fluids become more diluted, and the kidneys excrete more (and more dilute) urine, getting rid of the excess that has been taken in.

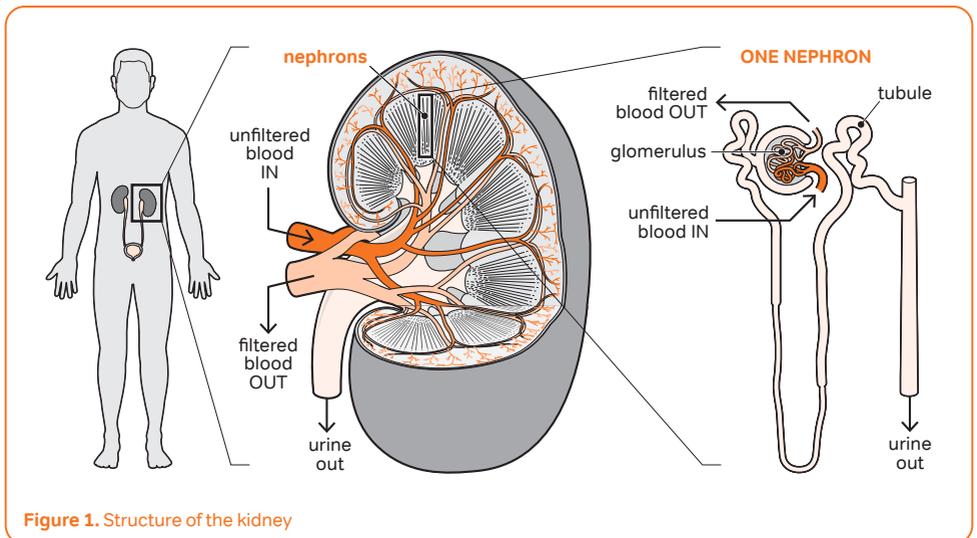


Figure 1. Structure of the kidney

## 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 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

# 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.**

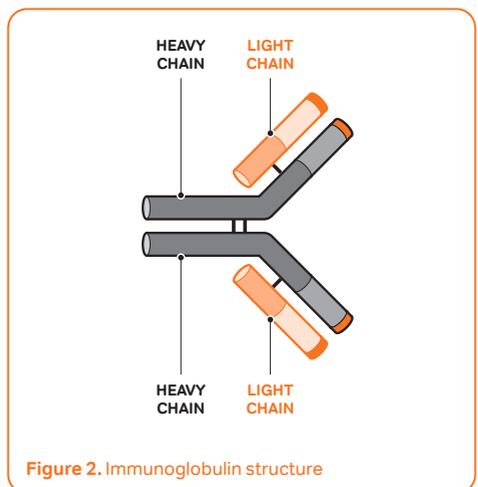
Myeloma kidney disease can occur for a variety of reasons. The abnormal protein produced by myeloma cells can damage the kidneys by blocking the tubules. Other complications of myeloma, such as dehydration and a high calcium level (hypercalcaemia), as well as some of the drugs used to treat myeloma,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

## 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 about 20% of patients, the myeloma cells produce only light chains (sometimes called Bence Jones proteins) and no whole immunoglobulins at all. This is called 'light chain' or 'Bence Jones' myeloma.

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

The excessive amount of 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 often combine with another protein called **Tamm Horsfall protein**. The combination of light chains with Tamm Horsfall protein can produce a big protein that sticks in and blocks the tubule, rather than passing through into the urine. This can cause severe 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 worsening the damage.

### Hypercalcaemia

Bone is high in calcium and as it is broken down, a large amount of calcium is released into the blood. Myeloma commonly causes excess bone breakdown and this can cause high blood calcium levels (**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 vulnerable to infection. Kidney infections can, if not treated promptly, worsen kidney impairment, 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 between two and three litres (three to five pints) of fluid per day (see page 12). However, if you require **dialysis**, the amount of fluid that you can drink may be restricted, sometimes to less than one litre (a pint and a half) a day.

## Drugs used in myeloma

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

For example, some **bisphosphonates** used to treat myeloma bone disease can be toxic to the kidneys. This is because these drugs are removed from the body via the kidneys – this can put additional strain on them

if they are already damaged. This includes zoledronic acid (Zometa<sup>®</sup>) and disodium pamidronate.

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

**Non-steroidal anti-inflammatory drugs (NSAIDs)** – such as ibuprofen (Nurofen<sup>®</sup>), diclofenac and high-dose aspirin (300mg) – can be toxic to the kidneys and are therefore 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 harm your kidneys.

# What are the symptoms of myeloma kidney disease?

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**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 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 doctor 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 means that kidney problems are usually picked up early.

# Tests used to detect and monitor myeloma kidney disease

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**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 that measures 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 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). It is possible to calculate an exact value for the GFR but this is now rarely done because of the need for specialised equipment.

A normal eGFR is 60 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'll have regularly – such as those measuring your red and **white blood cell**

levels and calcium levels – can also provide an indication of 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. A test that is often carried out is a 24-hour urine specimen to check light chain levels present in the urine that you are passing
- Kidney biopsy – a definitive diagnosis of kidney disease may be made by taking a small sample of kidney tissue so that the cells can be examined under a microscope for damage. This test is only occasionally done in myeloma patients

# The treatment and management of myeloma kidney disease

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**There are different ways to treat and manage myeloma kidney disease, depending on its underlying cause.**

It is possible for myeloma kidney disease to be reversed, and in some cases the kidneys can fully recover. However, in about 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 of treating myeloma kidney disease is to treat the underlying myeloma and in doing so, reduce the light chain and/or paraprotein level.

If you have kidney damage at diagnosis, you may be given high-dose steroids (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 these 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 fluid. In many cases, kidney disease can be reversible and a high fluid intake may be enough in itself to reverse the damage.

Unless you have been advised to restrict your fluid intake, you should try to drink between two and three litres (three to five pints) of fluid per day. Most liquids count, so drink as many glasses of water, sparkling water, juice or squash, decaf tea or milk as you can. Caffeinated tea, coffee and alcohol can be included, but in moderation. Your medical team will give you advice about this.

If you are severely dehydrated you may be given fluid directly into a vein (intravenous). 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 that you can drink may be restricted, sometimes to less than one litre (a pint and a half) a day. 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.

### **Treating hypercalcaemia with bisphosphonates**

Bisphosphonates are drugs that help to prevent and slow down bone breakdown and are used in the treatment of myeloma bone disease. By preventing the increased breakdown of the bones, less calcium is released from the bones and hypercalcaemia may be prevented or resolved.

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 can be very painful and unpleasant and usually happens when bacteria travel up from your bladder into one or both of your kidneys. The signs and symptoms of a kidney infection may include:

- Fever (temperature above 38°C)
- A temperature below 35.5°C
- Chills and sweating
- Burning sensation or pain when passing urine, or a frequent need to urinate
- Nausea/vomiting
- Pain in the abdomen

If treated promptly, a kidney infection doesn't cause serious harm but it might make you feel very unwell. If a kidney infection isn't 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 are:

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

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

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

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

If patients have myeloma kidney disease, the 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. A potentially serious complication can occur when a large number of myeloma cells are killed rapidly by anti-myeloma treatment and release toxins into the bloodstream. If the kidneys are not working as well as they should, they cannot efficiently remove these toxins from the blood. The toxins can then cause a number of problems in the kidneys, potentially leading to kidney failure.

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 greatest myeloma cell death occurs).

## Dialysis

In the majority of patients, kidney damage is temporary and the kidneys can recover. However, in up to one in ten patients (10%), 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 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**

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 dialysis line (plastic tube) is inserted into a vein in the top of your 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.

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 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 (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.

Kidney specialists will discuss this with you as an option if your kidneys don't recover and you need long-term dialysis treatment. More about living day-to-day on long-term dialysis can be found on page 17.

# Living with myeloma kidney disease

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**The added complication of kidney disease in addition to myeloma can be worrying for you and your family.**

However, there are a number of things you can do to look after your kidneys. These will 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 fluids, and about dealing with 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 14)
- Be aware of the symptoms of kidney infection and report them as soon as possible (see page 13)
- Look out for any signs or symptoms of kidney damage and report them to your doctor or nurse as soon as possible (see page 10)

## Living on dialysis

If you need dialysis, this can be disruptive to your day-to-day life because of the time involved for both types of dialysis.

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

In myeloma patients who ultimately recover kidney function, the average time on dialysis treatment is around three 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 another salt called potassium, 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 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 doctor or nurse will give you more detailed information on diet while on dialysis.

While you are on dialysis the amount of fluid that you can drink will also be restricted (see page 13). Your medical team will advise you.

### **Side effects of dialysis**

Both haemodialysis and peritoneal dialysis 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) and how to manage them.

## Fatigue

Fatigue, where you feel tired and exhausted all 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 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

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

There are several treatment options that may be of some help in improving the symptoms of fatigue.

You may want to consult a dietician because your diet may need to be adjusted 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 consult your

dialysis unit because the amount of fluid used during dialysis may need to be adjusted.

## Infection

Haemodialysis patients have an increased risk of developing sepsis.

This is 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 38°C (100.4°F) or above
- Dizziness, related to a decrease in blood pressure, or a worsening of low blood pressure



**If you have a high temperature or you think you might be developing sepsis, contact your dialysis unit immediately for advice, or alternatively phone NHS 111.**

If you develop sepsis, you will need to be admitted to hospital and treated with injections of antibiotics.

## 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 build-up 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

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### **Myeloma kidney disease is a common complication of myeloma and adds to the overall burden of myeloma.**

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 are putting great effort into tackling the barriers to early diagnosis, hoping that this will reduce the number of patients who develop kidney disease before they start myeloma treatment.

# Questions for your doctor/healthcare team

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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 medical team. Order your free copy from Myeloma UK at [myeloma.org.uk/publications](https://myeloma.org.uk/publications)

## Medical terms explained

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**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.

**Bisphosphonate:** A type of drug that slows down or prevents bone damage.

**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 erythropoietin (EPO) can be given to patients who are anaemic.

**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 relieved by rest or sleep.

**Glomerular filtration rate (GFR):** A measurement of how well the kidneys are working by testing the amount of creatinine in the blood.

**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 and organs that protect the body against infection and disease.

**Immunoglobulins (antibodies):** 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.

**Light chain:** The smaller of two components that make up the structure of antibodies (or immunoglobulins). There are two types of light chain, kappa and lambda.

**Malignant:** A term for cancerous cells which have the ability to spread.

**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 drug used to prevent or treat pain which do not contain steroids.

**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 produce antibodies (immunoglobulins) to fight infection.

**Quality of life:** A term that refers to a person's level of comfort, enjoyment, and ability to pursue 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 (often referred to as stable disease).

**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 drug or treatment, for example fatigue or nausea.

**Tamm Horsfall protein:** The most abundant protein in normal urine. Its function is not well understood, but it can bind to free light chains in the kidney, causing damage.

**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, such as oily fish (e.g. 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 type of bisphosphonate drug which is given by intravenous infusion.

# Useful organisations

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## **Carers UK**

[www.carersuk.org](http://www.carersuk.org)

**0808 808 7777**

Provides advice, information and support for carers.

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## **Citizens Advice**

[www.citizensadvice.org.uk](http://www.citizensadvice.org.uk)

**England: 03444 111 444**

**Wales: 03444 77 20 20**

**Scotland: call your local office**

**Northern Ireland: use Advice NI, visit [adviceni.net](http://adviceni.net)**

Offers advice about debt and consumer issues, benefits, housing, legal matters and employment.

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## **Macmillan Cancer Support**

[www.macmillan.org.uk](http://www.macmillan.org.uk)

**0808 808 0000**

Provides practical, medical and financial information and support to all cancer patients and their carers.

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## **Maggie's**

[www.maggiescentres.org](http://www.maggiescentres.org)

**0300 123 1801**

Provides free practical, emotional and social support to people with cancer and their family and friends.

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## **Mind**

[www.mind.org.uk](http://www.mind.org.uk)

**0300 123 3393**

Provides advice and support to empower anyone experiencing mental health problems.

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## **NHS 111 Service**

[www.nhs.uk/111](http://www.nhs.uk/111)

**111**

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

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# We're here for everything a diagnosis of myeloma brings

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



Get answers to your questions by emailing **AskTheNurse@myeloma.org.uk**



Learn about myeloma from experts and meet other patients at our **Patient and Family Myeloma Infodays**.



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



Join your nearest **Myeloma Support Group** to meet up and talk to other people face to face.



Visit **myeloma.org.uk**, a one-stop-shop for information on myeloma; from news on the latest research and drug discovery to articles on support, treatment and care.



Watch **Myeloma TV**, videos about myeloma presented by experts, patients and family members.



Use the **Discussion Forum** for the opportunity to share experiences and advice about living with myeloma.



myelomauk

# We need your help

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**Thanks to our generous supporters we are able to provide information and support to patients and their families, as well as fund vital research that will help patients live longer and with a better quality of life.**

Myeloma UK receives no core government funding. We rely on fundraising activities and donations.

You can support Myeloma UK by:

- **Making a single donation or setting up a Direct Debit**

Online at [myeloma.org.uk/donate](https://myeloma.org.uk/donate)

Over the phone **0131 557 3332**

Or by posting a cheque payable to **Myeloma UK** to:

Myeloma UK, 22 Logie Mill, Beaverbank Business Park, Edinburgh, EH7 4HG

- **Fundraising** – fundraising is a positive way of making a difference and every pound raised helps. As myeloma is a rare, relatively unknown cancer, fundraising is also a great way to raise awareness
- **Leaving a gift in your will** – legacies are an important source of income for Myeloma UK and help us to continue providing practical support and advice to myeloma patients and their families. They also help us to undertake research into the causes of myeloma and investigate new treatments



However you decide to raise funds, our Fundraising Team is here to support you. Contact us on **0131 557 3332** or email [fundraising@myeloma.org.uk](mailto:fundraising@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](https://myeloma.org.uk/pifeedback) or email any comments to [patientinfo@myeloma.org.uk](mailto:patientinfo@myeloma.org.uk)

For a list of references used to develop our resources, visit [myeloma.org.uk/references](https://myeloma.org.uk/references)



## Symptoms and complications Infoguide: Myeloma and the kidney



### 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**

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