

AL amyloidosis and the kidney

Symptoms and complications of AL amyloidosis Infosheet

This Infosheet provides information on how AL amyloidosis can affect the kidneys, what the symptoms of AL amyloidosis kidney disease are, how it can be treated and some tips for self-management.

In AL amyloidosis, an abnormal protein called amyloid is produced and accumulates in tissues and organs. The build-up of amyloid protein is called an amyloid deposit. Deposits can occur in various organs or tissues, including the kidneys, and affect their function. The kidneys and the heart are the organs most commonly affected by amyloid deposits.

What do the kidneys do?

Most healthy people have two kidneys which carry out many essential functions in the body, such as:

- Filtering the blood to remove waste products and excess fluid from the body
- Returning essential vitamins, glucose and hormones back into the bloodstream

- Maintaining the levels of salt (e.g. sodium and potassium) and water in the body
- Controlling blood pressure
- Producing a number of essential hormones (e.g. erythropoietin, vitamin D and renin) to maintain normal body processes and function

What is AL amyloidosis kidney disease?

In normal kidney function (also known as renal function), blood is filtered through very small structures of the kidney, the glomeruli, which remove waste products from the blood and excrete them from the body in the urine.

In AL amyloidosis kidney disease, amyloid deposits are too large to be filtered by the glomeruli and they get stuck and accumulate instead of passing through into the urine. This causes damage to the kidneys and they are no longer able to maintain a normal salt and water balance. This means that excess fluid and harmful waste products build up causing damage to the body.

In addition to this, proteins which are required by the body leak into the urine and are excreted.

Occasionally, a tiny amount of blood itself can also be excreted in the urine.

Kidney disease can cause several symptoms and complications and if left untreated can cause kidney failure.

What are the symptoms and complications of AL amyloidosis kidney disease?

Kidney disease can develop slowly and may not cause symptoms in the early stages (known as chronic kidney disease) or it can develop very suddenly over hours or days (known as acute kidney disease). The symptoms of kidney disease vary depending on the extent of the damage.

One of the most common symptoms of kidney disease is oedema (the retention of abnormally large amounts of fluid in the body). This occurs when the kidneys are not working properly and excess fluid builds up, causing symptoms such as:

- Swelling in the lower legs
- Swelling in the abdomen
- Rapid increase in body weight, e.g. more than three pounds in two days

- Coughing and/or trouble breathing, especially at night/when lying flat
- Tiredness

Other symptoms and complications of kidney disease include:

- Blood in urine (detectable with a urine test)
- Frothy urine (caused by protein in the urine)
- Anaemia (damaged kidneys are less able to produce the hormone erythropoietin which is involved in the production of red blood cells)
- Loss of appetite

Diagnosing and monitoring AL amyloidosis kidney disease

There are a number of tests which are used to diagnose and monitor kidney disease. Early diagnosis of kidney disease is important to limit any damage and stop further damage from occurring.

Blood tests

Blood tests are used at diagnosis and during treatment to measure the levels of waste products produced by the body, such as creatinine and urea, present in your blood. These levels are used to determine the function of the

kidneys, a calculation known as glomerular filtration rate (GFR). High levels of creatinine and urea indicate that the kidneys are not working normally.

Urine tests

Urine tests are used to measure the amount of blood and/or protein in the urine, the presence of either of these indicates that the kidneys are not functioning properly. A urine test may also be used to detect amyloid in the urine.

Serum Amyloid P Component Scintigraphy (SAP scan)

A SAP scan is a scanning procedure that shows the distribution and amount of amyloid in the organs without the need for biopsies. This scan is only performed at the National Amyloidosis Centre in London.

For more information see the [AL amyloidosis – SAP scan Infosheet](#) from Myeloma UK

Kidney biopsy

A kidney biopsy involves the removal of a small sample of your kidney tissue which is then examined in a laboratory for

amyloid deposits. A SAP scan is usually preferred over a biopsy because it is less invasive.

For more information on tests and investigations in AL amyloidosis, see [AL amyloidosis – Your Essential Guide](#) from Myeloma UK

How is AL amyloidosis kidney disease treated and managed?

The most effective treatment for AL amyloidosis kidney disease is to treat the underlying AL amyloidosis, while controlling the symptoms and complications of the kidney disease. By treating the AL amyloidosis itself, the amount of abnormal amyloid produced is reduced or controlled, resulting in fewer deposits in the kidneys which cause damage. There are several treatments that can help to control the symptoms and complications.

For an overview of the treatment for AL amyloidosis see [AL amyloidosis – Your Essential Guide](#) from Myeloma UK

Controlling blood pressure

Your doctor can prescribe treatment that can help to maintain a steady blood pressure. Well controlled

blood pressure has been shown to slow down the progression of kidney disease.

Diuretics

Your doctor may prescribe diuretics (a type of drug used to promote the excretion of fluids by increasing urine production) to help reduce water retention.

Anaemia

Erythropoietin (EPO) is a hormone normally produced by the kidneys and plays an important role in the production of red blood cells. When kidneys are damaged and unable to produce erythropoietin, the body doesn't produce enough red blood cells, which can cause anaemia.

Anaemia is usually controlled at home with iron tablets, however, some patients continue to be anaemic and may need to have other treatments, for example EPO injections or blood transfusions. Injections with synthetic EPO signal the bone marrow to produce red blood cells and relieve the symptoms of anaemia.

Dialysis

If your kidney disease progresses to such an extent that your kidneys lose the ability to function, this is known as kidney failure which

requires dialysis. Only around 1 in 100 people with severe kidney disease will go on to develop kidney failure.

Dialysis is usually required immediately after failure has been identified. There are two different types of dialysis available to patients: **haemodialysis** and **peritoneal dialysis**.

Haemodialysis – the most common type of dialysis. During haemodialysis, a plastic tube (haemodialysis line) is attached to a needle in your arm and removes blood for filtering. The blood passes along the tube and into an external dialysis machine. This machine removes waste products from the blood, before the blood is passed back into your arm along another tube. This is usually required for three days a week in four hour sessions in hospital.

Peritoneal dialysis – uses the inside lining of your abdomen (the peritoneum) as a filter, rather than a machine, which means it can usually be performed at home. The peritoneum is made up of lots tiny blood vessels and works in a similar way to the kidneys. This dialysis process involves a catheter (a tube inserted into the body to administer drugs and fluids) being inserted through an incision in your belly

button and into the space inside your abdomen (the peritoneal cavity). The catheter is left in place permanently.

Dialysis fluid is pumped into the peritoneal cavity through the catheter. As blood passes through the blood vessels lining the peritoneal cavity, waste products and excess fluid move from the blood and into the dialysis fluid. The used dialysis fluid is drained into a bag a few hours later and replaced with fresh fluid. Peritoneal dialysis lasts around 30 to 40 minutes and the fluid is changed around four times a day. It can be run overnight.

Tips for self-management

You can effectively monitor and manage some symptoms and complications, such as oedema and blood pressure, at home and it is important to do so. This includes:

- Controlling your **fluid intake**. Fluid intake should be steady and limited to your doctor or nurse's recommendation, (usually not more than 1.5 litres a day)
- Controlling your **salt intake**. Limiting the amount of salt in your food is important, along with following a healthy, balanced diet. This can help reduce water

retention. A dietician can be helpful for personalised dietary advice

- Monitoring your **weight** daily with a set of accurate digital scales. Digital scales are recommended as small weight changes can be monitored more precisely. Keep a diary of your weight and make a note of any changes. If you have a weight gain of more than three pounds in 2 days, let your doctor or nurse know as soon as possible as this could indicate that you are retaining too much fluid
- **Exercising** gently and regularly to increase general well-being and improve circulation
- Avoiding **non-steroidal anti-inflammatory drugs** (NSAIDs), such as aspirin and ibuprofen, as they can be toxic to the kidneys and should be avoided by patients with AL amyloidosis kidney disease. It is important that you inform your doctor or nurse about any non-prescription drugs, vitamins or supplements that you may be taking to ensure they will not damage your kidneys

For more information see the [Diet and nutrition in AL amyloidosis Infosheet](#) from Myeloma UK

Summary

AL amyloidosis patients are at a higher risk of developing kidney disease caused by the build-up of amyloid deposits in their kidneys. AL amyloidosis kidney disease can have a significant impact on your quality of life, especially if left untreated. It is important to be watchful for the early symptoms of kidney disease and report them to your doctor or nurse as soon as possible to minimise long term damage. There are several ways to manage and treat kidney disease, which include limiting salt and fluid intake, diuretics and daily weight checks.

About this Infosheet

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

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

To give feedback about this publication, email myelomauk@myeloma.org.uk or fill in a short survey at myeloma.org.uk/pifedback

Other information available from Myeloma UK

Myeloma UK has a range of publications covering all aspects of AL amyloidosis, its treatment and management. Download these publications from myeloma.org.uk/publications

To talk to one of our Information Specialists about any aspect of AL amyloidosis, call our Myeloma UK Infoline on [0800 980 3332](tel:08009803332) or [1800 937 773](tel:1800937773) from Ireland.

The Infoline is open from Monday to Friday, 9am to 5pm and is free to phone from anywhere in the UK and Ireland.

Information and support about AL amyloidosis is also available around the clock at myeloma.org.uk/amyloidosis



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Call the Myeloma Infoline on

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Registered Charity No: SC026116



Published by:	Myeloma UK
Publication date:	February 2017
Last updated:	March 2019
Review date:	February 2022

Myeloma Awareness Week • 21–27 June