AL amyloidosis
Your Essential Guide
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**Disclaimer:** The information in this publication 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.
Basic facts

Amyloid can build up in the kidneys, heart, liver, spleen, nerves, or digestive system

Amyloid can affect two or more organs at the same time

AL amyloidosis does not affect the brain

AL amyloidosis is a relatively rare condition, with approximately 500 - 600 people diagnosed in the UK each year
What is AL amyloidosis?

The term ‘amyloidosis’ is a general term used for a group of conditions where an abnormal protein, called amyloid, accumulates in the tissues. The build-up of amyloid protein is called an ‘amyloid deposit’ which can occur in various organs or tissues and cause problems.

Different types of amyloidosis are named according to the type of amyloid protein which is produced. All begin with the initial ‘A’ which stands for amyloidosis, followed by another letter(s) which identifies the particular amyloid protein, for example: AL amyloidosis, AA amyloidosis and ATTR amyloidosis.

In AL amyloidosis it is abnormal plasma cells in the bone marrow that produce the amyloid protein. In AL amyloidosis the amyloid proteins are light chains (the ‘L’ in ‘AL’ stands for ‘light chain’). Light chains are normally part of healthy antibodies, also known as immunoglobulins, produced by healthy plasma cells (see Figure 1).

The amyloid protein is only broken down very slowly by the body and starts to build up in the tissues and organs - gradually damaging their function and causing symptoms. This build-up can happen almost anywhere in the body. Each patient has a different pattern of amyloid deposition, with different organs affected.

Figure 1. Immunoglobulin structure
AL amyloidosis and myeloma

Although the amyloid deposits in AL amyloidosis are not themselves cancerous, the condition may occasionally be associated with myeloma (a plasma cell cancer).

You may have been diagnosed with AL amyloidosis alone or, less commonly, you may have developed AL amyloidosis after being diagnosed with myeloma. It is rare, but possible, for someone diagnosed with AL amyloidosis to later develop myeloma in addition to their AL amyloidosis.

Regardless of whether or not a patient has myeloma associated with their amyloidosis, the treatments for AL amyloidosis are similar to those for myeloma.

For more information about myeloma see Myeloma An Introduction from Myeloma UK.
The symptoms of AL amyloidosis

AL amyloidosis can affect the body in several ways, causing a number of symptoms. This is due to the amyloid protein being deposited in almost any organ in the body.

The symptoms you have will depend on which organ or organs are most affected by amyloid deposits. Most patients will have more than one organ affected by amyloid deposits.

The organ that is most affected will be referred to as the ‘dominant organ’.

Be honest with your doctor and nurse about any problems you are having. Describing them as accurately and as early on as possible will help you get the right treatment as soon as possible. This can also reduce the number and severity of the complications associated with AL amyloidosis.

The most common symptoms of AL amyloidosis, how they may affect you, and how they are managed are described below.

It is important to remember that not everyone will have all of these and that effective supportive treatments and strategies to prevent or control them are available.

Non-specific symptoms
These are common and may have been present for some time before diagnosis. They include fatigue, weakness, weight loss and loss of appetite.

Shoulder pad sign
Sometimes amyloid is deposited in the soft tissues around the shoulders; this leads to characteristic swelling of both shoulders known as the shoulder pad sign. This may be the first sign of AL amyloidosis.
The kidneys
Kidney disease is very common in AL amyloidosis patients. Kidney disease usually develops slowly. Amyloid deposits in the kidneys typically make the kidneys leak proteins and may also affect the ability of the kidney to filter the blood. This can lead to a condition called nephrotic syndrome in which the lower legs typically become swollen (oedema). In some cases amyloid deposits mean that the kidneys can no longer purify the blood; this is called kidney or renal failure. If kidney disease is severe, a treatment called dialysis may be needed to purify the blood.

For more information see the AL amyloidosis and the kidney Infosheet from Myeloma UK

The heart
About one half to two thirds of all patients with AL amyloidosis have amyloid deposits in the heart which causes it to become unusually stiff and unable to work properly. This can cause shortness of breath with even the slightest effort.

Amyloid deposits can also affect the way in which the heart beat is controlled. This can lead to abnormal heart beats (arrhythmia) which can cause increase in breathlessness, dizziness or fainting, sometimes on exertion or after eating. Chest pain, however, is rare in AL amyloidosis.

When AL amyloidosis affects the heart, it is called cardiac amyloidosis.

For more information see the AL amyloidosis and the heart Infosheet from Myeloma UK

The nervous system
Amyloid deposits can affect the nerves of the hands, feet and lower legs and may cause pain, numbness and tingling. This is called peripheral neuropathy.

AL amyloidosis can also affect nerves controlling blood pressure, heart rate, gut
movement and other body functions. This can cause a variety of symptoms including dizziness when standing too quickly, nausea and diarrhoea and/or constipation. This is called **autonomic neuropathy**.

**For more information see the AL amyloidosis and autonomic neuropathy Infosheet from Myeloma UK**

**The digestive system**

Amyloid deposits in the digestive system (stomach and intestines or gut), can cause a feeling of nausea, diarrhoea or a sensation that the stomach is full after eating small amounts. Amyloidosis can also reduce the body’s ability to absorb nutrients from food, leading to weight loss.

**The skin**

AL amyloidosis can affect the skin and nails. This can lead to easy bruising, skin rashes or nail changes. This is particularly obvious when it affects the skin around the eyes. Bruising around the eyes may lead to a very distinctive appearance, known as raccoon eyes.

**Carpal tunnel syndrome**

Patients with AL amyloidosis may develop a condition called carpal tunnel syndrome. This happens when amyloid deposits in the wrist press on nerves, causing tingling and pain in the wrists and pins and needles in the hands and fingers. Carpal tunnel syndrome is quite common and only rarely caused by AL amyloidosis.

**Macroglossia**

*Macroglossia* is a marked enlargement of the tongue because of amyloid deposits. When it is present this often causes difficulty in eating or in speaking. Macroglossia is not very common in AL amyloidosis but it is very rarely seen in any other condition. If a patient has marked macroglossia it is very likely that this is caused by AL amyloidosis.
Diagnostic tests and investigations

To diagnose and monitor AL amyloidosis, several tests and investigations need to be carried out.

Tests and investigations are done to:

- Establish a diagnosis and the extent of the condition
- Determine a treatment plan and monitor progress
- Detect complications of the condition so they can be monitored and treated

Guidelines for AL amyloidosis recommend that, if possible, people should attend the National Amyloidosis Centre (NAC) in London for a series of tests before they are diagnosed. This is the only centre in the UK specialising in amyloidosis and is part of the University College London Division of Medicine. The NAC carries out an individually tailored assessment and evaluation over 1 – 2 days, and hospital or hotel accommodation is provided. Transport to and from London may also be provided for patients who need it for medical reasons.

Some tests are done mainly to confirm a diagnosis of AL amyloidosis and are rarely, if at all, repeated. Other tests are very helpful to monitor how AL amyloidosis is progressing and how it is responding to treatment.

Tests usually done at diagnosis

Tissue biopsies

A tissue biopsy involves the removal of a small sample of tissue for microscopic examination. In AL amyloidosis this is done to look for evidence of amyloid deposits.

If an organ is not working properly, AL amyloidosis may be one of a number of possible causes. Where possible, a biopsy will be taken from the affected organ and tests for AL amyloidosis and other conditions will be done.
Tissue samples may be taken from the:
- Kidney
- Nerve
- Heart
- Gut (stomach or intestines)
- Skin
- Thyroid gland (in the neck)
- Lymph nodes (glands)
- Bone marrow
- Abdominal fat

You will be given details of what kind of biopsy is being taken and how this will be done. It is very unusual for a patient to have more than one biopsy sample taken, or to have samples taken from more than one organ. This is because all that is needed to confirm the diagnosis is evidence of amyloid deposits anywhere in the body. Repeat tissue biopsies are not usually used to monitor the condition.

A biopsy can help to confirm a suspected AL amyloidosis diagnosis. This is because results from other tests, such as blood tests, can be caused by other diseases.

Additionally, a biopsy sample is only a small piece of tissue and the amount of amyloid can vary in different places. This means that not finding amyloid in a biopsy sample does not completely rule out a diagnosis of AL amyloidosis. Therefore it is used as part of a number of tests to diagnose the condition.

**Tests at diagnosis and to monitor AL amyloidosis**

The tests described below are used not only to diagnose AL amyloidosis but also to measure response to treatment and to monitor AL amyloidosis activity over time. Many of these tests are repeated regularly throughout all stages of your treatment and care.

**Blood tests**

A full **blood count** measures the levels of different cells in your blood.
The most important measures are:

- **Red blood cell** count – a low count shows that you have **anaemia**
- **White blood cell** counts – low counts of some or all of the different white blood cells indicate that you are at greater risk of infection
- **Platelet** counts – a low count shows that you are at an increased risk of bleeding or bruising more easily than normal

Some of the treatments given for AL amyloidosis can affect the bone marrow and reduce the production of normal blood cells. This is why doctors will regularly check your full blood count.

**Bone marrow aspirate and trephine biopsy**

There are two types of bone marrow tests that may be carried out. These involve the removal of some liquid bone marrow (a bone marrow aspirate) and/or the removal of a 1 – 2 cm core of bone marrow tissue (a bone marrow biopsy).

Both bone marrow tests are fairly invasive procedures and must be carried out by a skilled specialist.

Bone marrow samples are usually taken from the pelvic bone (Figure 2). A needle is inserted through the skin and into the bone and a sample is drawn up by suction through a syringe.

The procedures are carried out under local **anaesthetic**, with or without sedation, and last only a few minutes.

Once your diagnosis has been confirmed, you may need a bone marrow test to assess response to treatment. You will usually have a repeat bone marrow test if you have a relapse which means that your light chains have started to increase again.

You may need bone marrow biopsies more often if you are in a **clinical trial**.
Kidney function

Kidney function can be affected by amyloid deposits and by some of the drugs used to treat AL amyloidosis.

Regular blood tests at diagnosis and during treatment to measure levels of creatinine and urea are used to monitor your kidney function.

Serum Free Light Chain (sFLC/dFLC)

The Serum Free Light Chain Assay (also called sFLC assay or Freelite® test) measures free light chains. It involves taking a sample of your blood from a vein in your arm or hand. You can usually have this sample taken at the same time as other routine blood tests.

As well as being important in diagnosing AL amyloidosis, changes in the levels of free light chains in the blood are usually a good indicator of changes in the activity of AL amyloidosis, as the higher the free light chain level, the more quickly amyloid is deposited. For this reason, free light chain measurements are done regularly to see how well treatment is working and to check that the AL amyloidosis is...
remaining stable during periods when you are not receiving treatment.

The sFLC assay can also be used to measure the amount of normal and abnormal light chains in the blood. The difference between the two is called the difference free light chain or dFLC, and can be used as another way of checking how AL amyloidosis is responding to treatment.

You may have to wait a number of days to receive the results from the sFLC assay as it is regarded as a specialised test that requires experience in its interpretation and use, which means some hospitals have to send your sample away for testing.

There are other free light chain tests in development but none have yet been proved to be suitable for use in patients with amyloidosis.

**The SAP scan**

This investigation is available at the National Amyloidosis Centre in London and is performed routinely for most patients who are referred there for evaluation of their AL amyloidosis.

Serum amyloid P component (SAP) is a normal protein found in the blood that binds to amyloid deposits. In healthy people there are very small amounts of SAP and this is only present in the bloodstream, not in the organs.

AL amyloidosis patients have large quantities of SAP coating the amyloid deposits in their organs. This coating shows up clearly in the SAP scan so the scan shows where in the body the amyloid is located and which organs are affected. The SAP test is less effective at showing amyloid in hollow or moving organs like the heart and gut, or in the skin and nerves.

The SAP scan has reduced the need for organ biopsies as a way of monitoring AL amyloidosis.

For more information see the AL amyloidosis - Serum Free Light Chain Assay Infosheet from Myeloma UK
This investigation is available at the NAC in London only.
The scan may be repeated every 6 – 12 months to check how well treatment is working and to monitor the amount and location of the amyloid deposits to help guide ongoing treatment.

Through the use of the SAP scan it has been found that amyloid deposits often decrease and break up when the number of abnormal plasma cells is controlled. Reducing the number of abnormal plasma cells means that less amyloid is produced.

Over time this is usually accompanied by an improvement in organ function and general health. It may take some time to lead to an improvement in signs or symptoms, but it may be reassuring to know that the SAP scan is showing a reduction in the amyloid deposits.

**Other tests**

You may have other tests or investigations during diagnosis and monitoring of AL amyloidosis, including:

- **Echocardiogram** (also called an echo) is a scan that uses ultrasound to show an image of the heart
- **Electrocardiogram (ECG)** is a test that measures the electrical activity of the heart
- **NT-proBNP and cTnT** are blood tests which show if there is heart damage caused by amyloid. They may be used when you are diagnosed to check if your heart is affected and again later to check for the effectiveness of treatment
- **CT (computerised tomography)** is a scan that uses X-rays to create detailed images of organs and structures in the body

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For more information see the AL amyloidosis - SAP Scan Infosheet from Myeloma UK
MRI (magnetic resonance imaging) is a scan that uses a combination of radio-waves, a powerful magnetic field and a computer to produce images of organs and tissues within the body. This is especially useful for assessing amyloid deposition in the heart.

Additional blood and urine tests
It is important to repeat tests and investigations as AL amyloidosis does not usually remain stable over a long time. The amount of amyloid deposits may increase, or, if treatment is working, decrease. It is vital to have a clear picture of AL amyloidosis in each patient to inform the choice of treatment and to monitor response to treatment.
Treatment for AL amyloidosis

Treatments for AL amyloidosis can be effective at controlling the condition, reducing symptoms and improving quality of life. Unfortunately, though, there is no cure for AL amyloidosis.

In general, treatment is given to:
- Reduce the level of abnormal plasma cells responsible for producing the amyloid protein, as far as possible
- Prevent further tissue or organ damage
- Control the AL amyloidosis if it has come back again (relapse)
- Improve quality of life
- Prolong life

Types of treatment
The treatment and management of AL amyloidosis fall into two categories. These are:

Treatments to control the AL amyloidosis and prevent new amyloid deposits
There are a number of different treatments available which may be used in several different combinations. These include:
- Chemotherapy
- Steroids
- High-dose therapy and stem cell transplantation (HDT-SCT)
- Immunomodulatory drugs e.g. thalidomide, lenalidomide (Revlimid®)
- Proteasome inhibitors e.g. bortezomib (Velcade®)

Supportive care treatments
These treatments aim to control and alleviate symptoms and complications caused by AL amyloidosis. These include:
- Treatments that control fluids
- Antibiotics
- Anti-emetics (to prevent nausea and vomiting)
- Diet supplements
- Treatment of heart disease
There is some overlap between these categories, since any treatment that controls your AL amyloidosis will have the added benefit of reducing any symptoms and complications.

The length of treatment varies depending on the type of treatment being used and the stage at which the treatment is being given. Treatment is usually given over a number of weeks and 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 of treatment.
The specific treatment combination prescribed for AL amyloidosis patients depends on the individual and what is most suitable for them.

Treatment is usually most effective when two or more drugs with different but complementary mechanisms of action are given in combination.

**Chemotherapy**

Chemotherapy drugs, such as cyclophosphamide and melphalan, work by damaging the DNA of the abnormal plasma cells in the bone marrow. This stops them from multiplying and causes them to die.

Chemotherapy drugs attack all rapidly multiplying cells in the body. This includes the abnormal plasma cells, but also may affect other rapidly multiplying cells such as normal developing blood cells in the bone marrow, hair follicles and the lining of the mouth and stomach. This is the cause of some of the side-effects of chemotherapy treatment.

Cyclophosphamide and melphalan, when given in combination, are usually given orally (by mouth in tablet form). Some types of chemotherapy are given by intravenous infusion (into a vein).

Side-effects may include nausea, vomiting, diarrhoea, infections, sore mouth and hair loss. Chemotherapy can also potentially cause infertility so it is important that you talk to your doctor about the possibility of this occurring.

**Steroids**

Steroids are drugs which mimic certain hormones in the body. They work in many different ways
to stop abnormal plasma cells growing.

The most commonly used steroids used in AL amyloidosis treatment are **dexamethasone** and **prednisolone**.

Steroids are usually given orally as tablets, or more rarely intravenously. Tablets should be taken with food or milk to help protect the lining of the stomach from irritation. It is also recommended steroids are taken in the morning to prevent sleep disturbance.

Side-effects of steroids may include stomach pain, increased blood sugar, increased risk of infection, increased appetite, mood changes, sleep disturbance and muscle weakness. One particular side-effect of steroids, which is common in patients with AL amyloidosis, is fluid retention and worsening oedema. This should be carefully monitored and may require additional treatment to aid removal of the excess fluid.

**Immunomodulatory drugs**

Immunomodulatory drug (IMiD) are thought to work in a number of ways, including by stimulating the **immune system** to attack and kill abnormal plasma cells.

IMiDs used in AL amyloidosis treatment include thalidomide and its derivatives lenalidomide and **pomalidomide (Imnovid®)**.

IMiDs are given orally.

Side-effects may include drowsiness and constipation, damage to the nerves in the hands and feet resulting in tingling, numbness, increased sensitivity and pain (called peripheral neuropathy), increased risk of blood clots, skin rash or itchiness. If taken during pregnancy, IMiDs can harm the developing baby – you will be given very clear advice on preventing this risk.
Proteasome inhibitors

Proteasome inhibitors work by temporarily blocking the actions of proteasomes. Proteasomes are involved in the removal, breakdown and recycling of damaged or unwanted proteins. Proteasome inhibitors block proteasome function which results in a build-up of proteins, which become toxic, causing the cell to die. The abnormal plasma cells are more sensitive to this action than normal healthy cells are.

Proteasome inhibitors used in AL amyloidosis include bortezomib and carfilzomib (Kyprolis®).

Bortezomib can be given as an intravenous injection or subcutaneous injection (under the skin into the tummy or thigh).

Side-effects may include peripheral neuropathy, reduction in white blood cells, nausea, vomiting, diarrhoea, skin rash or itchiness, and fatigue.

For more information about specific treatments for AL amyloidosis contact Myeloma UK

How long will my treatment last?

The total length of one treatment course often depends on which treatment you are taking and how you respond to it, but a single course is unlikely to last less than three months or longer than eight months.

A course of treatment is given in cycles, e.g. treatment over a few days or weeks, followed by several days or weeks without treatment before the next dose is given. This is to give the healthy cells time to recover between treatments.

If you have specific questions about how long your treatment course will last, your doctor is the best person to answer them.

Unfortunately, different treatment combinations do not always work for everyone. Your doctor will monitor your progress carefully and if you do not respond to one
particular treatment, it will be stopped and other options will be explored.

All patients receiving treatment for their AL amyloidosis should go back to the NAC to be assessed after completing the first three cycles. This enables any response to be measured and treatment adjusted accordingly early on.

**Side-effects**

Each drug has its own side-effects and the same drug can produce different reactions in different people. Most side-effects are only short-term, can be managed with supportive treatments and gradually disappear once the treatment has stopped.

Sometimes it may be necessary to reduce the dosage, or frequency of treatment, or to change from one drug to another if the side-effects are too much to manage.

You should be given patient information leaflets for all of your drugs. If you are not, ask your doctor or pharmacist for copies.

If you have any side-effects that you think may be due to your treatment, it is important that you tell your doctor or nurse straight away. They may be able to suggest ways of reducing or relieving the symptoms of your side-effects, perhaps by changing or reducing the dose or by prescribing supportive drugs.

For more information see the AL amyloidosis – Steroids and Peripheral Neuropathy Infosheets from Myeloma UK
Treatment combinations

Commonly used initial treatment combinations include:

- CTD – cyclophosphamide, thalidomide and dexamethasone
- CVD – cyclophosphamide, bortezomib and dexamethasone
- VMD – bortezomib, melphalan and dexamethasone
- Mel-dex – melphalan and dexamethasone
- Bortezomib and dexamethasone
Intensive initial treatment

For younger and/or fitter patients, initial chemotherapy-based treatment will almost always be followed by much more intensive treatment known as high-dose therapy and stem cell transplantation (HDT-SCT).

HDT-SCT is an intensive treatment which is associated with potentially greater side-effects and complications than standard or lower dose chemotherapy. It is therefore only offered to AL amyloidosis patients who are generally fit and healthy up to the age of 70, have no significant heart damage and have good kidney function.

What is high-dose therapy and stem cell transplantation and why is it used?

Despite its effectiveness, a major drawback of chemotherapy is the inability to give high doses safely. This is because high doses of chemotherapy not only kill the abnormal plasma cells but also the blood-forming stem cells in the bone marrow. This results in blood cell production being severely affected, with blood counts falling to dangerously low levels causing potentially life-threatening problems.

HDT-SCT provides a solution to this drawback. Stem cells are collected from the patient before a high dose of chemotherapy is given to kill the abnormal plasma cells, and then the stem cells are returned to the patient. This effectively 'rescues' the patient’s bone marrow, allowing blood cell production to continue. This type of stem cell transplantation is known as an autologous stem cell transplant.

Very rarely, a patient may receive stem cells from a donor. This is known as an allogeneic stem cell transplant. This is done very rarely in AL amyloidosis.
The stem cell transplant procedure

Steps 1 to 3 – Stem cell mobilisation and collection
You will be given treatment to stimulate stem cells to multiply and travel from the bone marrow into the blood stream, so that enough stem cells can be collected for the transplant.

Stem cells are collected from your blood prior to receiving high-dose therapy by a process called apheresis. This involves passing the blood through a machine, which separates and collects the stem cells and returns the remainder of the blood back to your body.

When enough stem cells have been collected they are frozen and stored until they are needed for the transplant. The minimum number of stem cells needed for a successful transplant is two million per kilogram of body weight. However, it is almost always the aim to collect enough for two transplants (both as a contingency and to store for a potential second transplant in the future).

Step 4 and 5 – High-dose chemotherapy and stem cell transplant
You will receive the high-dose therapy with the chemotherapy drug melphalan as an inpatient. Within a day or so after receiving the high-dose therapy, your stem cells will be given back to you intravenously, in a similar way to a blood transfusion.

Step 6 – Recovery
Once the stem cells are back in the bloodstream, they return to the bone marrow, where they settle and develop into new blood cells. This vital process is called engraftment and takes about two weeks.

Most patients stay in hospital until their blood counts return to a safe level. This normally means spending two to four weeks as an inpatient. During this time you may feel quite unwell and be kept...
in protective isolation in hospital to help you avoid infection. Blood and platelet transfusions may be required until the bone marrow recovers and antibiotics may be given to prevent infection.

The HDT-SCT process can be quite debilitating and after the procedure a period of several weeks of slow recovery at home is often needed.

Advantages/disadvantages

The main advantage of high-dose therapy and stem cell transplantation is the possibility of achieving an excellent response and long remission. Disadvantages include the risk of significant side-effects and the reality that relapses still occur.

For more information see the AL amyloidosis - High-Dose Therapy and Stem Cell Transplantation Infoguide from Myeloma UK

Figure 3. Steps involved in high-dose therapy and autologous stem cell transplantation

1. induction treatment
2. stem cell mobilization
3. stem cell collection
4. high-dose melphalan
5. autologous stem cell transplant
Organ transplantation

For a very small number of patients, heart or kidney transplantation may be appropriate. This might take place before or after treatment for the AL amyloidosis, depending on a number of individual factors.

If you are likely to be considered for organ transplantation, your doctor will discuss this with you.
How do I know if my treatment has worked?

The aim of treatment is to destroy the abnormal plasma cells to stop additional amyloid being deposited in organs.

Over time, the body may then be able to break down the existing amyloid deposits resulting in a gradual improvement in organ function, reduction in symptoms and improvement in quality of life.

In order to find out how you are responding to treatment, several tests are carried out on a regular basis.

These tests may vary from patient to patient, but generally will include regular blood and urine tests, occasional bone marrow aspirates and SAP scans. The earliest sign that treatment may be working is a fall in the free light chain level measured by the Serum Free Light Chain Assay (sFLC).

Measuring response to treatment

Haematological response

Haematological response is the response of the free light chains (and paraprotein, when present) to treatment. See Table 2 for the different response levels and their criteria.

Organ response

Organ response looks at whether the function of organs affected by AL amyloidosis has improved. There is nearly always a substantial delay between the haematological response and the organ response.

A combination of patient symptoms, blood tests and imaging tests may be used to assess the function of different organs affected by AL amyloidosis. See Appendix 2 for more details.

For more information see the AL amyloidosis – Serum Free Light Chain Assay Infosheet from Myeloma UK
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<td>Complete haematological response</td>
<td>Normal free light chain levels, Normal free light chain ratio, No detectable paraprotein in the blood, No detectable light chain in the urine, No abnormal plasma cells on bone marrow biopsy</td>
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<tr>
<td>Very good partial response</td>
<td>A reduction in the difference free light chain (dFLC) to below 40mg/l. If the dFLC cannot be used, reduction in paraprotein is used instead</td>
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<tr>
<td>Partial response</td>
<td>At least 50% reduction in the dFLC</td>
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*Table 2: Measuring the response to treatment*
Treatment for relapsed or refractory AL amyloidosis

Although there are many effective treatments for AL amyloidosis, currently there is no cure. This means that after every successful treatment and period of plateau or remission, you will relapse and amyloid deposits will build up again.

If your AL amyloidosis returns after a period of remission or plateau, this is called a relapse. If your AL amyloidosis is not responsive to treatment, it is referred to as refractory. Treatments work in many different ways, so if you have not responded well to one type of treatment, this does not necessarily mean that you won’t respond well to a different type of treatment.

Being told your AL amyloidosis is not responding to treatment or has returned can be a very disappointing and distressing time for patients, their families and carers. Talking things over with your doctor, family, or another patient can help. Myeloma UK may also be a good source of support and information at this time.

What treatments are available for relapsing AL amyloidosis?

The same treatment may be repeated for relapsed patients who had a good and long lasting response to the initial treatment. In other relapsed and refractory patients, a different treatment will need to be given.

Allogeneic transplant

For a very small number of younger and/or fitter patients with good kidney function, an allogeneic transplant may be considered after relapse. This is where stem cells from a donor with a matched tissue type (usually a sibling) are used for the transplant.
Allogeneic transplants are not recommended for AL amyloidosis other than as part of a clinical trial. Allogeneic transplants have important differences compared with autologous stem cell transplants both in the potential benefits and the risks involved. Allogeneic transplants aim to use the immune system of the donor to help fight against the patient’s AL amyloidosis. The donated stem cells are transplanted into the patient where they mature into functioning cells of the immune system. These can then potentially attack abnormal plasma cells – this effect is known as ‘graft-versus-tumour’ and is thought to be responsible for the lower rate of relapse that can be seen following an allogeneic transplant compared to an autologous transplant.

The main disadvantage of an allogeneic transplant is the risk of graft-versus-host disease (GVHD), which is a potentially life-threatening condition. This is when the donated cells not only attack the abnormal plasma cells but also destroy the patient’s own body tissue. GVHD is a major problem and is one of the reasons why allogeneic transplants have a higher mortality rate than autologous transplants.
Making treatment decisions

There is an increasing range of effective treatments for AL amyloidosis. Generally, the best treatment for you will take account of:

- Your general health, including any other medical conditions you have
- Your age
- Your personal circumstances and lifestyle, your priorities and preferences
- The nature/characteristics of your AL amyloidosis (for example, which organs are affected by amyloid)
- The number of abnormal plasma cells are in your bone marrow
- Any previous treatment you have had

Making an informed decision is important and you should take as much time as you need to make one. However, in some situations there may be an urgent need to start treatment and if this is the case your doctor will discuss this with you.

To help you understand more about AL amyloidosis and the treatment options available, try to collect as much information as you feel you need. Information is available from doctors, nurses, other patients, the internet and Myeloma UK. In talking to other patients it is important to remember that each person’s experience of AL amyloidosis is different. A treatment which works well for one patient will not necessarily be suitable or effective for someone else.

Listing the pros and cons of each option is a good way to help you to decide on the best treatment for you. Talking things over with your family, friends or another patient can help to clarify your thoughts.
Asking for a second opinion
AL amyloidosis is a rare and complex disease and choosing the right treatment can sometimes be as challenging for doctors as it is for patients. You may feel that you want more than one opinion to be sure that the diagnosis is correct, that the treatment plan is appropriate for your situation and that all other options have been considered.

Doctors are normally happy to arrange for another opinion and you should not feel that asking for one will offend them or the medical team. You may, however, find it easier to approach your GP about this.

Sometimes patients have difficulty communicating with their doctor and want the chance to talk to another one. In this circumstance, you might ask to see a different doctor in the same hospital or to have another opinion at another hospital.

While you do not have an automatic right to more than one opinion, this will usually be available, and if it is not, there should be a justifiable reason for refusing your request.

What if I want to try alternative therapies?
Some people do not want any conventional medical treatment and instead prefer to try a different approach using special diets, alternative therapies or remedies.

Conventional treatments have been successfully tested in clinical trials and doctors have a clear understanding of how they work. It is important to appreciate that almost no alternative approaches have been studied in the same way, there is currently no evidence that they work in treating AL amyloidosis, and they are not necessarily safe or harmless.

If you choose to use alternative ways of trying to control your AL amyloidosis, it is essential to
discuss this with your doctor as there are potential risks involved and you may choose to try conventional treatment at a later date.

Alternative approaches to treatment should not be confused with **complementary therapies**. Complementary therapies are used alongside, and complementary to, conventional treatment. Complementary therapies include relaxation and meditation, massage, reflexology and aromatherapy. Before starting any complementary therapy it is important to discuss it with your doctor.

**What if I don’t want any treatment?**

Some people do not want to have any treatment for their AL amyloidosis. The decision not to have treatment is a very personal one and you should talk this through with your doctor.

If you choose not to have treatment for your AL amyloidosis, there are many supportive measures available to help alleviate symptoms of the condition.

Whether or not you choose to have treatment, it may be helpful to be seen by a **palliative care specialist**, who will be able to provide expertise in symptom control and supportive care.

**Who is involved in my treatment and care?**

Guidelines for AL amyloidosis recommend that, if possible, all patients should be seen at the NAC at regular intervals.

The NAC will agree treatment for your AL amyloidosis, some of which may be provided by your local or regional hospital, working jointly with the NAC.
Your relationship with your healthcare team

Your relationship with your medical team will involve trust and collaboration. You should feel comfortable asking questions and discussing treatment options with them. Learning more about AL amyloidosis and the different treatments that are available will help you to communicate more easily with your medical team and help you to make informed decisions about your care.

Sometimes medical professionals forget that most patients do not understand medical jargon. If you do not understand something, don’t be afraid to say so and ask for information to be given in everyday language (layman’s terms). Doctors and nurses would rather explain something twice than have you go home confused and worried. Many people find it helpful to receive written information they can take away and read at home.

Remember that there are likely to be uncertainties and that your doctor may not be able to answer specific questions about the future. For example, you may want to know how successful your treatment is likely to be before you decide to have it. Whilst your doctor will be able to give you average figures, they will not be able to predict exactly how you are going to respond to the treatment.
Over the past few years, new developments in the treatment and management of myeloma and its related conditions, like AL amyloidosis, have had a significant impact on the way they are treated. Research is continuing to develop new treatments and to use existing treatments in a better, more effective way.

A great deal of research is going on to find more effective and less toxic drugs for myeloma. This may benefit AL amyloidosis patients because the same drugs are used for the treatment of both.

Clinical trials in AL amyloidosis are investigating treatments to help target and clear amyloid deposits. For example, a drug called miridesap has been developed which, in an early phase trial, cleared almost all SAP from the blood. This prevented new amyloid deposits forming in patients, but did not help to clear existing ones.

Researchers are now looking into a combination of miridesap and a monoclonal antibody drug called dezamizumab, an antibody against SAP. It is hoped that this combination will both prevent new amyloid deposits forming and clear existing ones to provide an effective way of treating AL amyloidosis in the future. However, there is still a great deal of research needed before this new treatment enters routine use.

Another monoclonal antibody drug, NEOD001, is being investigated in the phase II PRONTO trial and phase III VITAL trial for the treatment of cardiac amyloidosis and newly diagnosed AL amyloidosis respectively.

The ALchemy study is an ongoing study of AL amyloidosis.
chemotherapy treatment at the NAC. This was funded by Myeloma UK and has been the largest study of its kind in AL amyloidosis. It has led to important changes in practice; the most important of which has been finding that patients’ response to treatment should be evaluated after 3 months of treatment (rather than 6 months), and those who do not have a good response to treatment should have their treatment adjusted as early as possible.

Patients who are included in the study will continue to be followed up to see how the study improves their long-term outcomes.
Coping with symptoms and side-effects

There are a number of symptoms and side-effects that AL amyloidosis and its treatment can cause. These can greatly affect you not just physically but psychologically too, as having to live with them day-to-day can be frustrating and tiring.

There are things you can do to help you cope with symptoms and side-effects. For some of them, at-home management is particularly important.

**Fluid overload**
One of the most common and serious side-effects in AL amyloidosis is fluid overload. This happens when your kidneys are unable to pass enough urine and fluid collects in your body. This can happen if your AL amyloidosis has affected your heart or kidneys. Fluid overload causes a variety of symptoms including:

- Swelling in the feet, ankles or lower legs (oedema)
- Swelling in the abdomen (ascites)
- Rapid increase in body weight due to fluid build-up
- Tiredness
- Difficulty breathing
- Coughing and/or trouble breathing at night (especially when lying flat)

There are three specific things you can do to reduce the risk of fluid overload and to recognise it when it happens. These are known as the three Ds:

- Diet
- Diuretics
- Daily weight checks

**Diet**
Fluid overload happens when you are taking in more fluid than your kidneys can remove.
To prevent this, you should keep your fluid intake steady. Try to keep it to no more than 1.5 litres (about 3 pints) a day. This includes all fluids – water, tea, coffee, soft drinks and alcohol. It is wise to limit your alcohol intake but you do not have to give up alcoholic drinks completely.

Excess salt can contribute to fluid overload so you should also keep the amount of salt you eat to a minimum. As well as reducing the amount you add while cooking or before eating, you should be aware of how much salt is in any ready-made food you buy, as it can contain a surprising amount. Check food labels to make sure you’re not eating too much salt.

Foods which have a particularly high salt content include:
- Processed foods
- Ready meals
- Crisps and snacks
- Bacon

- Canned meats
- Sausages
- Canned soups
- Smoked fish

It may be helpful to talk to a dietician to get detailed advice on a healthy diet.

**Diuretics**

Even with careful diet control, you may still have fluid overload. This can be treated with diuretics, often called water tablets, which are drugs that help your kidneys to pass more fluid. This helps your body to get rid of salt as well as excess fluid.

Diuretics can help to ease ankle swelling and breathlessness caused by fluid overload. Diuretics are only effective if you continue to control your salt and fluid intake.
**Daily weighing**

It is important to recognise and treat fluid overload early. Usually, one of the first signs of excessive fluid is an increase in weight.

If your doctor thinks you are at risk of developing fluid overload, you may be asked to weigh yourself daily.

You should do this at the same time each day. It is best to do this as soon as you have passed urine in the morning and while wearing your underwear only. It is usual for your weight to vary a little day to day, but if your weight increases several days in a row, even slightly, you should tell your doctor or nurse. They may wish to start you on diuretics or adjust your diuretic treatment.

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**Raised blood pressure**

If you have kidney damage caused by amyloidosis, then you may also have raised blood pressure (hypertension). Some standard drugs used to treat high blood pressure or heart failure can make things worse for people with amyloid heart disease. This makes it more complicated to treat high blood pressure if you have amyloid heart disease.

If you are being treated for high blood pressure by a doctor other than your amyloidosis specialist, it is very important to make sure they know about your amyloidosis. If they are not sure how to deal with this, it may be helpful to suggest they contact the NAC.

You can help to reduce the risk of high blood pressure by not putting on weight and by taking exercise. You should not overdo exercise but a reasonable amount of exercise is helpful.
Pain and peripheral neuropathy

One of the main causes of pain in AL amyloidosis is peripheral neuropathy. This is the term used to describe damage to the nerves that make up the peripheral nervous system. Peripheral neuropathy may be caused either by amyloid deposits in the nerves, or by some of the treatments for AL amyloidosis. The nerves most commonly affected are those of the hands and feet, and this causes symptoms such as altered sensation, tingling, numbness or pain (referred to as neuropathic pain).

There is no standard treatment for peripheral neuropathy so an individual approach is used to try and control the symptoms. This may include neuropathic pain-relieving medication such as amitriptyline or gabapentin, vitamin supplements and complementary therapies.

Tips for managing pain:

- Take pain-killers regularly as prescribed. They will be more effective if you take them before the pain takes hold.
- If you are taking your pain-killers as prescribed but your pain is not being managed properly, speak to your doctor or nurse. They will be able to change the dosage or give you a different pain-killer to help. There are many different pain-relieving treatments available and it is often a case of trial and error to find the best pain treatment plan.
- Avoid taking non-steroidal anti-inflammatory drugs (NSAIDs), e.g. ibuprofen, as they can damage the kidneys.
- Be honest with your doctor or nurse about any pain you are experiencing. You should not feel you have to put on a brave face - remember that your doctor and nurse are there to help you.

For more information see the AL amyloidosis - Peripheral Neuropathy Infosheet from Myeloma UK.
Describe your pain as accurately as you can, i.e. dull and aching, piercing, transient or constant. It may be helpful to keep a diary of when you feel pain and what it is like.

Learn relaxation, meditation or visualisation techniques. A combination of these can be helpful in relieving pain. They need to be practiced regularly in order to get maximum benefit.

Try to reduce your anxiety levels – anxiety and stress can make pain worse. Talking, counselling and complementary therapies can help.

Massage may help with relaxation and pain, but make sure it is gentle to avoid further discomfort or damage to your bones. Only use an experienced massage therapist and explain your situation to them.

Find something to take your mind off the pain – watching television, a favourite film, listening to music or chatting to a friend won’t make your pain go away but it can distract your attention from it.

Make use of heat and cold – hot water bottles and ice packs can be effective pain relievers. Wrap them in a towel before placing them onto the skin. They may only give short-term relief and you may need to alternate between warm and cold.

Make sure you are sitting comfortably – the way you sit or lie can affect your pain. Try using special v-shaped pillows to help you get more comfortable when sitting in bed.

If your pain is not being controlled by your prescribed pain medication, or with the addition of any of the above, ask your doctor or nurse for a referral to a pain specialist who will be able to adjust your pain medication for a better response.
Fatigue
Fatigue is an extreme ongoing tiredness caused by the condition and/or its treatment and it is a very common problem for AL amyloidosis patients. Living with fatigue can have a huge impact on your quality of life and can be extremely challenging for you and your family.

Fatigue is not caused by a lack of sleep but poor sleep can worsen it. It may be caused or made worse by many things, including anaemia (low red blood cell count), poor nutrition, pain, drugs used to treat AL amyloidosis, anxiety and depression. These can affect daily activities, relationships with others and self-esteem, which can lead to increasing feelings of isolation, fear and loss of confidence. These can be very draining emotions and easily increase feelings of fatigue.

Fatigue can stop you doing the things that matter to you and can be upsetting and distressing to cope with.

You should make sure that your doctor is aware that fatigue is a problem for you and how it affects your day-to-day life, so they can help.

There are a number of things that you can do to help cope with fatigue:

- Make sure you are eating a well-balanced diet. You may not feel like eating but it is important to give your body enough nutrients so that it can carry on functioning properly.
- Ask your doctor to refer you to a dietician if you are having trouble eating.
- Make getting enough sleep a priority and get into a routine of going to bed and getting up at the same time every day.
- If your AL amyloidosis is affecting your heart or kidneys, you may find it
difficult to sleep flat so having a few extra pillows or even a back rest for the bed can make a substantial difference

- Try complementary therapies
- Take gentle exercise every day - this can actually help to improve your energy levels. You can ask your doctor to refer you to a physiotherapist who can recommend some suitable exercises for you, but remember that you may be limited in what you can do, depending on your organ involvement
- Pace yourself and keep a diary so that you can recognise when you are most likely to need rest and when you are most likely to be able to do chores or gentle exercise
- Allow yourself rest periods during the day. This can be a nap or just a sit/lie down

**Nausea and vomiting**

Two of the main side-effects associated with some AL amyloidosis treatments are nausea and vomiting. Many AL amyloidosis patients find these side-effects very upsetting but there are things that can be done to control them.

It is important to tell your doctor if you are vomiting as it can lead to dehydration and other complications if left untreated.

Tips for managing nausea and vomiting:

- Take your anti-emetic medications regularly as prescribed. Do not wait until you feel sick, as the drugs won’t be as effective this way
- If you find the anti-emetics you have been prescribed are not effective when taking them as prescribed, ask to try a different one as there are several types available

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**For more information see the AL amyloidosis - Fatigue Infosheet from Myeloma UK**

www.myeloma.org.uk/amyloidosis
Sometimes you may feel sick before having your treatment, especially if treatment has made you sick previously. Ask your doctor or nurse if it is ok to take your anti-sickness treatment before your AL amyloidosis treatment to help avoid this.

Certain smells may make you feel sick, for example strong food smells. Avoid cooking foods with strong smells and keep the window open during food preparation.

If hospital smells make you feel sick, try putting light perfume onto a handkerchief that you can use to help mask the smell.

Certain scents may help with nausea, for example lavender can be soothing. Speak to a complementary therapist who should be able to recommend some aromatherapy scents to help with your nausea.

Ginger flavoured drinks may help settle your stomach.

Mints or chewing gum can help with nausea and freshen your mouth after vomiting.

Try to take your mind off how you feel – talk to people, watch a film or listen to soothing music to distract yourself.

Relaxing breathing exercises or lying down in a darkened room may help to reduce feelings of nausea.

Fresh air may also help calm nausea – try sitting near an open window or outside.

It is important to keep drinking as vomiting can dehydrate you. Allow your stomach to rest after vomiting then sip drinks such as still or sparkling water or fizzy juice drinks.

If vomiting is severe, fluid can be replaced by special preparations available through your GP or from a chemist.
Hair loss/thinning

Hair loss is common with some kinds of chemotherapy. Not all chemotherapy drugs cause hair loss, and different AL amyloidosis patients may be affected in different ways by the same drug.

With the chemotherapy drugs used to treat AL amyloidosis, you may just experience some thinning of the hair, rather than losing it all.

Going through hair loss or thinning can be very emotional as it can affect your self-image and your identity. Speak to your nurse about how it is making you feel and how best to manage it.

If you do lose some or all of your hair, remember that it will grow back once your treatment has finished. When your hair does start to grow back it is often very fine, but you will probably have a full head of hair after three to six months. You may also find that your new hair is curlier or finer than it was before and it may be a slightly different colour.

Cutting your hair short before treatment can give you a sense of control over your appearance and may keep it looking better during loss and re-growth.

You’re likely to feel the cold more so some patients find soft hats, hoods, headscarves or wigs useful.

Many hospitals have a wig fitting service available, so if you think you may want a wig, ask your nurse about it. It may be easier to get a wig while you are in hospital receiving treatment. You can ask your hairdresser to style the wig on you to make sure it sits in the way you want it to.

In some cases you may lose your eyelashes and eyebrows as well. You can use make up like eyebrow pencils and eyeliner, and false eyelashes if you like. Some cancer support groups may have workshops
to help you learn application techniques, which may be available to AL amyloidosis patients as well. For example, Look Good Feel Better are a charity that hold workshops and classes that teach make up techniques for people with cancer.

**Mouth problems**

Some chemotherapy drugs can cause mucositis, which can make your mouth sore and inflamed, and sometimes cause blistering. Your mouth may become so sore that your eating is affected.

Your doctor will be able to give you something to treat or prevent these ulcers, such as a mouthwash. You can also help by making sure you clean your teeth gently and regularly using a soft toothbrush. You can try sucking on ice cubes or ice lollies during treatment to minimise the risk of mucositis.

**Tips for when you have mucositis:**

- Avoid food that sticks to the roof of your mouth such as chocolate, peanut butter or pastry
- Avoid spicy, salty or tangy foods
- Avoid mouthwashes that contain alcohol
- Drink cold drinks to soothe a sore mouth
- Moisten your food with gravy or sauces
- Allow food or drinks to cool slightly before consuming
- Drink through a straw
- Suck ice cubes or ice lollies
- Try using boiled sweets or chewing gum to stimulate saliva production

You may also notice a change in your sense of taste and find that some foods taste sweet, salty or metallic – this can be especially true after HDT-SCT.
Your sense of taste should return to normal after treatment has stopped.

Tips for when your sense of taste changes:

- Experiment with flavours in your food
- Try lots of different drinks and foods that you might not normally like to try and find something that tastes good
- It is better to eat something than nothing, so if you only want to eat a certain food you should try not to worry about it
- Ensure food smells appealing by seasoning it with sauces, herbs or marinades
- Try using plastic cutlery if your food tastes metallic

**Loss of appetite**

Your appetite may change over the course of your condition and treatment. Sometimes you may feel that you simply cannot face food. If this happens, try not to be discouraged by the fact that you are not hungry, and just eat when you can.

Eating little and often may help, or try planning meals around when you generally feel most hungry. For example, have a large breakfast and a smaller evening meal if you are always hungry in the morning. Always drink plenty of fluids, especially on days when you don’t feel like eating.

If your loss of appetite does not improve after a couple of weeks, or you lose a lot of weight, tell your doctor or nurse. They will be able to refer you to a dietician who can offer advice on how to eat a balanced diet and may recommend special build-up foods and drinks.

For more information see the AL amyloidosis – Diet and Nutrition and Mouthcare Infosheets from Myeloma UK
Infection

Infections are common in AL amyloidosis patients because AL amyloidosis and its treatments can reduce your white blood cell count, which affects your ability to fight infection. However, you can make some changes that might reduce your chance of infection. This is particularly important if you have recently undergone HDT-SCT, or if your white cell count is particularly low.

You should be vigilant for any signs of infection that you develop. It may be helpful to have a thermometer at home. Signs of infection include:

- Raised temperature (above 38 degrees centigrade)
- Feeling generally unwell or feverish
- Shivering
- Rash
- Cough or sore throat
- Diarrhoea

If you develop signs of an infection, it is important that you contact your doctor or the hospital immediately, especially if you are feeling unwell/shivering, as it may be important to start treatment as soon as possible. If you do not have contact details for your healthcare team for out-of-hours, phone NHS 111.

Tips for avoiding infection:

- The most important thing you can do to avoid infection is wash your hands – you should wash your hands with warm water and soap regularly, particularly after using the bathroom, before handling and eating food, and after returning home from being out, using public transport or visiting other busy places like the supermarket.
Carry alcohol hand gel when you’re out and about to make it easier to keep your hands clean.

Avoid being in enclosed spaces like buses or trains when they are very busy.

Ask people not to visit if they or anybody in their household have colds, flu, stomach bugs or other infections such as chickenpox and shingles.

All food should be as fresh as possible, fruit should be washed and meat should be cooked thoroughly.

Although it is important to avoid infections as much as possible, you should try to be reasonable and not shut yourself away or become paranoid. Take sensible precautions so that you can still enjoy life. Speak to your doctor or nurse if you are unsure about what you should be doing to avoid infection, particularly if your white blood cells count is low.
Living well with AL amyloidosis

Being diagnosed with AL amyloidosis affects every patient differently. It can be devastating and affect you and those closest to you in a number of ways.

The emotional impact of living with AL amyloidosis can be considerable and so coping with emotional changes and taking care of your mental health is important.

At first you might be overwhelmed, in shock and feel numb. Information may not sink in at this point but don’t worry, you will have many opportunities to ask questions.

Sometimes you might feel totally in control of your feelings, and at other times strong emotions may catch you unawares. You may feel a great deal of fear, anger and frustration. These feelings are common and a natural part of coming to terms with the diagnosis.

You may also experience a sense of relief that you now have an explanation for the symptoms you have been experiencing.

Coping with your emotions

However you’re feeling, it’s important to recognise your emotions and work out how to cope with them.

Although thinking positively can help you cope with the challenges of an AL amyloidosis diagnosis, you do not need to be upbeat all the time. It’s not a failure to take time out to feel sad, angry or frustrated. Acknowledge how you feel and take time to process your emotions.

Learning more about AL amyloidosis, your treatment options and life after a diagnosis of AL amyloidosis can help to ease worry, fear or anxiety.

Those around you may be feeling some of the same things as you so they will also need support. Talking together about how you feel can help.
Although sometimes you may feel optimistic, there may be other times when you feel overwhelmed. Many patients feel depressed or anxious at some stage. You may have difficulty sleeping, become irritable, or lose interest in the things that you normally enjoy. It is important to recognise these symptoms and to discuss them with your doctor or nurse.

**Relationships**

Changes to your relationships are not unusual after a diagnosis of AL amyloidosis. People will respond in different ways. They may not know how to respond or be overwhelmed by emotions and withdraw from you. Try not to take it personally. Talking openly and honestly with people will make it easier for everyone to understand what’s going on. People often take the cue from the patient so be clear about how you feel and what support you need from people.

**Sexual relationships**

Sometimes sexual relationships change after a diagnosis of AL amyloidosis. You or your partner may feel less keen to have sex. There can be many reasons for this. You may feel too tired or physically unable to enjoy a full sexual relationship. Stress and anxiety can often cause a loss of sexual desire (libido), or you may feel that sex is no longer important. Many drugs can also reduce sexual desire.

If a sexual relationship is important to you, talk to your partner about the way you feel, even though you may find it difficult to start the conversation. It is easy for people to feel rejected when a sexual relationship changes or ceases so talking about it is important to prevent misunderstandings. Try to discuss with your partner what level of intimacy feels comfortable and in time you may gradually return to a more physical relationship.
Don’t be embarrassed to talk to your GP, hospital doctor or nurse about problems with your sexual relationship. They are quite used to this sort of discussion, even if you are not, and they may be able to prescribe a treatment that can help.

**Emotional support**

Emotional support is important in helping you to live well with AL amyloidosis. It is very easy for patients and family members to feel isolated, and strong emotions often make it difficult to discuss worries or fears. Talking to someone who understands what is happening can ease these feelings of isolation.

You may need different sources of support at different times so it’s important to access whatever support you need when you need it.

**Counselling**

You may find it helpful to talk to a counsellor. Counsellors provide you with the chance to explore your feelings and experiences in a supportive, confidential environment. A counsellor does not give you advice but helps you to develop coping strategies and to find your own answers to the problems you are facing.

Counselling can have different focuses or methods, for example relationship counselling or Cognitive Behavioural Therapy (CBT).

Counselling may not always be available in your hospital, but your GP or hospital doctor should be able to refer you to a professionally trained counsellor in your area.

Alternatively you can contact the British Association for Counselling and Psychotherapy for a list of registered counsellors in your area.
Online support

The Discussion Forum on the Myeloma UK website is somewhere you can connect with others affected by AL amyloidosis, post messages to the group, ask questions and help to support each other. To join the Discussion Forum go to www.myeloma.org.uk/forum

Information and support about AL amyloidosis is also available online at www.myeloma.org.uk/amyloidosis

Support Groups

As AL amyloidosis is a rare condition, there are few AL amyloidosis-specific Support Groups in the UK. However, you may find a Myeloma, or Haematology, Support Group that meets locally.

Some Support Groups are run by patients and family members, others by healthcare workers or professional group facilitators.

If you are interested in setting up an AL amyloidosis Support Group, contact the Myeloma UK Infoline on 0800 980 3332.

There is also an online Support Group for anyone affected by AL amyloidosis, which can be found at www.amyloidssupportgroup.co.uk

Patient and Family AL amyloidosis Infodays

Myeloma UK holds an annual Patient and Family AL amyloidosis Infoday. This is a full-day educational meeting specifically for patients and families, where you can learn about the latest in the treatment and management of AL amyloidosis from a panel of AL amyloidosis experts. The Infoday also provides the opportunity to meet others affected by AL amyloidosis, to share experiences and gain support. For more information contact Myeloma UK on 0131 557 3332.
The Myeloma UK Infoline

To talk to one of our Information Specialists about any aspect of AL amyloidosis, call the Myeloma UK Infoline on 0800 980 3332. The Infoline is open from Monday to Friday, 9am to 5pm and is free to phone from anywhere in the UK.
A diagnosis of AL amyloidosis will affect more than just the patient. Caring for someone with AL amyloidosis can be challenging and unpredictable so ensuring that carers get the support they need is critically important.

When you are told that a family member or friend has AL amyloidosis you may feel shocked, upset and worried because the future is now uncertain. You may feel that you need to put on a brave face and disguise your feelings, but being honest about how you feel will help future communication between you and the person you know with AL amyloidosis.

You may not think of yourself as a carer because caring for someone you love is second nature, or a family duty. However, in many ways becoming a carer is like a new job; it may require learning new skills, dealing with a change in established roles and tackling demanding tasks.

You will probably have a lot of questions - ask the patient’s healthcare team if you can talk to them about what to expect, or call the Myeloma UK Infoline on 0800 980 3332 to talk to an Information Specialist.

Communication
Don’t feel that you have to talk about everything immediately and remember that listening is as important as talking. Taking time to listen to someone, without feeling you have to find solutions to any problems or worries can be very valuable.

Often we feel a need to stay in control by avoiding upsetting or difficult subjects. Keep in mind though that strong feelings are there anyway, and it may be that the patient
needs an opportunity now and then to let go. Being there with a caring approach will help.

Don’t be tempted to fill silences with reflex chatter – the patient may want time to think. Remember, not all communication is verbal; holding hands or placing your hand on someone can say as much as you need to. If you feel someone is silent because they are upset you can gently ask them questions. For example, “What are you thinking about?” may help to get them talking again. If you feel they would like to be alone then ask, “Would you like some time on your own now?”

**Getting information**

Although most of the attention from the medical staff is focused on the patient, remember that you are an important part of the team. You can ask questions about the things you want to know.

Sometimes there are questions the patient might not want to ask, or to know the answer to. These may be questions about what is likely to happen, or what plans to make. It may be difficult to ask these questions in front of them. If the patient has given their permission, ask the doctor or nurse if it would be possible to speak to them on your own.

Of course this can sometimes be reversed, with the patient wanting to ask questions that they are worried might upset you. Try to discuss things together before seeing the doctor or nurse so you know which questions you are going to ask.

**Getting help**

During treatment and recovery, AL amyloidosis patients will not be able to do as much as they did before. You may find you have to take on additional responsibilities or do things you rarely did before. Don’t let
yourself be overwhelmed by all this – healthcare professionals, relatives, friends and many voluntary organisations are there to help you.

Your GP can be a useful source of information and support and can put you in touch with services available in your area such as District Nurses, or Marie Curie nurses, home helps, hospice respite care and counsellors.

Try to take people up on their offers of help; this may also help them to feel better as they are able to do something for you. Sometimes people may want to help but may not understand the extent of what you do as a carer or may feel that offering help implies you are not doing a good job. Though you may find it difficult to ask for help, doing so can make others feel useful and reduce the demands on you.

Preparing food

It can be very frustrating watching someone not eating properly, especially if you have spent a lot of time and effort carefully preparing a suitable meal. It is important to understand that some of the side-effects of AL amyloidosis treatment can affect the patient’s appetite and even change their sense of taste. If the patient is experiencing side-effects due to their treatment, they may not be able to eat some days or may no longer enjoy meals they used to love. Try not to take it personally if they don’t eat the food you cook. It is unlikely to be a comment on the quality of your cooking.

Gently encourage them to eat but don’t push them. Have pre-prepared snacks to hand for when they feel like eating. Fresh and dried fruit and nuts, soups, breakfast cereals, yoghurt, dips, sandwiches and raw vegetables are easy to prepare and store.
**Looking after yourself**

It can be easy to stop prioritising your own needs as a carer. However, you are likely to burn out if you don’t take some time for yourself. Remember that you can’t look after anyone else if you don’t look after yourself.

Taking a break from caring can help you think things through and relieve stress and tiredness. Even taking a few hours off during the day and getting out of the house can make a huge difference to the way you feel and the amount of energy you have.

Take advantage of times when the patient is away from home. It may help to organise a rota of visitors to keep them busy, if they are up to it.

It is easy to feel that you have to be positive all the time and hide negative feelings from the patient you know. Thinking positively can help you face the challenges of AL amyloidosis, but don’t feel that you have to be upbeat all the time. Giving yourself a day off to feel sad does not mean that you have lost control or that you will not feel positive again.

If you feel things are getting on top of you, try to find the time to talk to someone such as your GP, specialist nurse or call the Myeloma UK Infoline on 0800 980 3332.

Tips for carers:

- Let other people help
- Learn about AL amyloidosis and its treatment
- Look after yourself – eat well, get enough sleep and visit your GP if you need to
- Take a day or a few hours off when you need to
- Ask your GP about nurse visits at home
Questions for your doctor / medical team

Diagnosis
- Which tests will I need to have?
- When will I get the results?
- Is my heart affected?
- Are my kidneys affected?
- Who will be my main point of contact at the hospital from now on?

Treatment
- What are my treatment options?
- What would happen if I chose not to have this treatment?
- How is the treatment given, how long will it take?
- Will a hospital visit/stay be needed?
- How will I feel before, during, and after this treatment?
- Will there be side-effects, when will I experience them and how long will they last?
- Will treatment affect my chances of having children in the future?

Post treatment
- How often should I have check-ups and blood tests?
- Will I receive any other treatments?
- How will I know if the AL amyloidosis has come back?

Carers
Carers often have different information needs. If you are a carer you will want to know what you will need to do for your family member/friend. You may want to ask the following questions:
- Will they require a stay in hospital and for how long?
- Will they require a lot of looking after?
- What kind of quality of life do you expect them to have?
- Who can I call in an emergency?
Tips

- Carry paper and a pen with you and write down questions when they occur to you.
- At the beginning of your consultation give your doctor a list of the questions you have written down.
- Always tell your doctor if you are taking any medicines you bought over the counter (without a prescription) or any supplements or complementary therapies you are using.
- Tell your doctor if you are experiencing any side-effects or symptoms. Try keeping a diary of your symptoms to help you keep track.
- Ask for a contact name and number for a member of your medical team and keep the number handy.
- Learn about AL amyloidosis and its treatment - download information from the Myeloma UK website.
- Call the Myeloma UK Infoline on 0800 980 3332 for information and emotional support.
- Join a Support Group - it can help to talk to other patients and relatives about how you feel. If there is no AL amyloidosis Support Group locally it may help to go to a Myeloma Support Group or a Haematology Support Group.
- Put aside time for rest and relaxation; make getting enough sleep a priority.
- Try to do something that you enjoy every day.
- Think positively, but allow yourself to have ‘off days’.

Infoline: 0800 980 3332
Medical terms explained

**Allogeneic stem cell transplant:** A procedure in which stem cells from a compatible donor (usually a sibling) are given to the patient following high-dose chemotherapy.

**Alternative therapy:** A therapy used instead of conventional treatment e.g. herbal remedies. There is no scientific evidence to prove that they are effective in the treatment of AL amyloidosis.

**Amyloid:** An abnormal protein that is deposited in tissues and organs.

**Amyloidosis:** A term for a group of conditions where an abnormal protein called amyloid is produced.

**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.

**Anaesthetic:** A type of drug used to temporarily reduce or take away sensation so that otherwise painful procedures or surgery can be performed. A general anaesthetic makes the patient unconscious and therefore unaware of what is happening. A local anaesthetic numbs the part of the body that would otherwise feel pain.

**Antibiotic:** A type of drug used to prevent or treat an infection caused by bacteria.

**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 (known as antigens), enabling other cells of the immune system to destroy and remove them.

**Anti-emetic:** A type of drug used to prevent or minimise nausea and vomiting.
**Apheresis:** A procedure used to collect stem cells from the blood using a machine which separates the stem cells and returns the remainder of the blood components to the patient or donor.

**Autologous stem cell transplant:** A procedure in which a patient’s own stem cells are collected, stored and then given back following high-dose chemotherapy.

**Autonomic neuropathy:** A group of symptoms caused by damage to the nerves that supply the internal organs.

**Biopsy:** The removal of a sample of living tissue for examination.

**Blood count:** The number of red blood cells, white blood cells and platelets in a sample of blood.

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

**Bortezomib (Velcade®):** A proteasome inhibitor which is given either intravenous infusion or subcutaneous injection.

**Carfilzomib (Kyprolis®):** A proteasome inhibitor which is given as an intravenous infusion.

**Chemotherapy:** A type of drug intended to kill cancer cells. Chemotherapy drugs can be injected into a vein (intravenous or IV) or swallowed as tablets (orally).

**Clinical trial:** A research study of new or existing treatment that involves patients. Trials may be designed to find better ways to prevent, detect, diagnose, or treat a condition or to answer specific scientific questions.

**Complementary therapy:** A therapy used alongside conventional treatment e.g. reflexology, acupuncture or reiki.
**Computerised tomography (CT or CAT scan):** A scanning procedure that uses X-rays and a computer to create detailed images of the body.

**Creatinine:** A normal waste product of muscle tissue breakdown which is found in blood. Creatinine is normally filtered through the kidneys and excreted in urine.

**Creatinine clearance:** The rate at which kidneys clear creatinine from the body and is used to assess kidney function.

**cTnT:** A protein which is released into the blood when heart muscle is damaged.

**Dexamethasone:** A steroid which is given orally or as an intravenous infusion.

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

**Difference Free Light Chain (dFLC):** A measurement which calculates the difference between the amounts of normal and abnormal light chains in the blood. This is one way of reporting the results of the serum free light chain assay. It can be used to monitor the response to treatment.

**Dominant organ:** The organ that is most affected by amyloid deposits.

**Echocardiogram (Echo):** A procedure which uses high frequency sound waves (ultrasound) to create images of the heart and surrounding tissues.

**Ejection fraction:** The amount of blood the heart pumps out each time it beats.

**Electrocardiogram (ECG):** A test used to detect and record the electrical impulses that the heart uses to make it beat.
**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.

**Free light chain:** A molecule which normally makes up part of an antibody. Called “free” light chain when it is not attached to the rest of the molecules that make up the antibody.

**Freelite®:** The brand name for the serum free light chain assay, a test used to detect and measure the type and amount of free light chains in the blood.

**High-dose therapy (HDT):** Treatment with high doses of chemotherapy given intravenously, usually via a central line (such as a HICKMAN® line), or a PICC line, prior to patients receiving healthy stem cells as part of the stem cell transplantation procedure. Also known as conditioning treatment.

**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 (known as antigens), enabling other cells of the immune system to destroy and remove them.

**Immunomodulatory drug (IMiD):** A type of drug used to act on the body’s immune system.

**Inpatient:** A patient who is admitted to hospital for treatment.

**Intravenous:** A slow drip of drugs or fluids into a vein over a set period of time.

**Ixazomib (Ninlaro®):** A proteasome inhibitor which is given orally.
Lenalidomide (Revlimid®): An immunomodulatory drug which is given orally.

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.

Macroglossia: Enlargement of the tongue.

Magnetic resonance imaging (MRI): A scanning procedure which involves a combination of radio-waves, a powerful magnetic field and a computer to produce images of any organ or tissue within the body. An MRI scan generates very detailed cross-sectional images of the area under investigation.

Melphalan: A chemotherapy drug which is given orally or intravenously.

Monoclonal antibody drug: A type of synthetic drug that mimics the actions of antibodies.

Myeloma (multiple myeloma): A cancer of the bone marrow caused by abnormal plasma cells which results in bone damage, low blood cell counts, increased infections and kidney damage.

Nephrotic syndrome: An abnormal condition of the kidney where the kidney filtering system does not function properly, causes fluid retention and results in large amounts of protein in the urine.

NT-proBNP test: A test which measures NT-proBNP levels and shows whether a patient has heart damage or failure.

Oedema: The retention of abnormally large amounts of fluid in the body. This causes swelling in the affected tissue.

Oral: By mouth.

Palliative care specialist: A doctor or nurse who specialises in care or treatment that concentrates on preventing and relieving symptoms and improving quality of life.
Panobinostat (Farydak®): A histone deacetylase inhibitor which is given orally.

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

Peripheral neuropathy: Damage to the nerves that make up the peripheral nervous system causing pain, tingling and altered sensation.

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

Plateau: A period of time when the AL amyloidosis, and the amyloid level, is relatively stable.

Platelets: A type of blood cell which are involved in blood clotting.

Pomalidomide (Imnovid®): A chemotherapy drug which is given as an intravenous infusion.

Proteasome: A type of cell structure involved in the removal, breakdown and recycling of damaged proteins or those that are no longer needed by the cell.

Proteasome inhibitor: A type of drug which interferes with the normal functioning of part of a cell called the proteasome. Abnormal plasma cells rely more heavily on proteasomes than normal, healthy cells; proteasomes inhibitors therefore cause abnormal plasma cells to die while leaving healthy cells less affected.

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: Blood cells which transport oxygen around the body.
**Refractory:** Disease that has failed to respond to treatment or has stopped responding to treatment.

**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 abnormal plasma cells and amyloid are no longer detectable, and there are no clinical symptoms of AL amyloidosis.

**Renal failure:** A condition in which the kidneys lose the ability to function properly.

**Serum Amyloid P component (SAP) scan:** A scanning procedure that shows the distribution and amount of amyloid in the body.

**Serum Free Light Chain Assay:** A test used to detect and measure the type and amount of free light chains in the blood.

**Side-effects:** Undesired effects caused by a drug or treatment, for example fatigue or nausea.

**Stem cells:** The type of cell from which all cells develop. Haematopoietic stem cells give rise to red blood cells, white blood cells and platelets. Haematopoietic stem cells are normally located in the bone marrow and can be harvested from the blood for transplant.

**Stem cell transplant:** The infusion of healthy stem cells into the body. This allows the bone marrow to recover and renew its blood-forming capacity following the administration of high-dose chemotherapy.

**Steroid:** A group of hormonal substances produced by the body. They are also produced synthetically and used to treat many conditions.

**Subcutaneous:** Under the skin.

**Thalidomide:** An immunomodulatory drug which is given orally.

**White blood cells:** A type of blood cell involved in the body’s immune system, which help to fight infection and disease.
## Appendix 1: Blood tests and normal ranges

<table>
<thead>
<tr>
<th>Blood tests</th>
<th>Test name</th>
<th>Normal range*</th>
<th>Notes</th>
</tr>
</thead>
<tbody>
<tr>
<td>Full blood count</td>
<td>White cell count</td>
<td>4.0 – 11.0 (x 10⁹/L)</td>
<td>A low count makes you less able to fight infections</td>
</tr>
<tr>
<td></td>
<td>Red cell count (men)</td>
<td>4.5 – 6.5 (x 10¹²/L)</td>
<td>A low red cell count is anaemia, which can cause fatigue</td>
</tr>
<tr>
<td></td>
<td>Red cell count (women)</td>
<td>3.9 – 5.6 (x 10¹²/L)</td>
<td></td>
</tr>
<tr>
<td></td>
<td>Haemoglobin (men)</td>
<td>135 – 180 (g/L)</td>
<td>A low haemoglobin level, also called anaemia, can cause fatigue</td>
</tr>
<tr>
<td></td>
<td>Haemoglobin (women)</td>
<td>115 – 160 (g/L)</td>
<td></td>
</tr>
<tr>
<td></td>
<td>Platelets</td>
<td>150 – 400 (x 10⁹/L)</td>
<td>A low count makes you bruise or bleed easily</td>
</tr>
<tr>
<td>Urea, electrolytes and creatinine</td>
<td>Urea</td>
<td>2.5 – 6.7 (mmol/L)</td>
<td>Measure of kidney function</td>
</tr>
<tr>
<td></td>
<td>Creatinine</td>
<td>70 – 150 (μmol/L)</td>
<td>Measure of kidney function</td>
</tr>
<tr>
<td>Proteins</td>
<td>Albumin</td>
<td>35 – 50 (g/L)</td>
<td>May be lowered in nephrotic syndrome</td>
</tr>
<tr>
<td>Free light chains</td>
<td>Kappa (κ) light chain</td>
<td>3.3 – 19.4 (mg/L)</td>
<td>Raised levels and an abnormal ratio in AL amyloidosis</td>
</tr>
<tr>
<td></td>
<td>Lambda (λ) light chain</td>
<td>5.71 – 26.3 (mg/L)</td>
<td></td>
</tr>
<tr>
<td></td>
<td>Ratio</td>
<td>0.26 – 1.65</td>
<td></td>
</tr>
</tbody>
</table>

* The normal range is an average, but each hospital laboratory has its own ‘normal range’ of values.
Explanation of units

\textbf{g/dL} \hspace{1cm} \text{number of grams there are in a decilitre (one tenth of a litre) of blood}

\textbf{g/L} \hspace{1cm} \text{number of grams there are in a litre of blood}

\textbf{ng/L} \hspace{1cm} \text{number of thousand millionths of a gram there are in a litre of blood}

\textbf{x \textit{10}^{9}/L} \hspace{1cm} \text{number of thousand million cells there are in a litre of blood}

\textbf{x \textit{10}^{12}/L} \hspace{1cm} \text{number of million million cells there are in a litre of blood}

\textbf{mmol/L} \hspace{1cm} \text{number of thousandths of a mole}^{**} \text{ in a litre of blood}

\textbf{umol/L} \hspace{1cm} \text{number of millionths of a mole}^{**} \text{ there are in a litre of blood}

\textbf{mole} \hspace{1cm} \text{a standard measurement for the amount of any chemical}

Please note that doctors do not use a litre of blood to make these measurements; they just take a small sample (a few millilitres) and then multiply up the results.
## Appendix 2: Organ response

<table>
<thead>
<tr>
<th>Organ</th>
<th>Improvement</th>
<th>Worsening (also called progressing)</th>
</tr>
</thead>
</table>
| Kidneys      | At least a 50% reduction in 24-hour urine protein loss (if urine protein was greater than 0.5 g/day before treatment)  
               or                                                                  | At least a 50% increase in 24-hour urine protein loss (at least 1 g/day)  
               or                                                                  | At least a 25% reduction in serum creatinine or creatinine clearance |
| Heart        | Results of specialised blood test called NT-proBNP show a response: >30% and 35 pmol/l decrease in patients with baseline NT-proBNP ≥77 pmol/l  
               or                                                                  | Results of specialised blood test NT-proBNP show a worsening/progression: >30% and > 35 pmol/l increase  
               or                                                                  | Results of a specialised blood test show cardiac troponin (cTnT) has increased by at least 33%  
               or                                                                  | At least a 10% decrease in ejection fraction |
| Liver        | At least a 50% improvement in liver function tests (decrease in abnormal alkaline phosphatase value) and reduction in liver size by at least 2cm | At least a 50% worsening in liver function tests (increase in abnormal alkaline phosphatase value) |
| Nervous system | Improvement in tests used to detect nerve injury called electromyogram or nerve conduction velocity | Worsening in tests used to detect nerve injury called electromyogram or nerve conduction velocity |
Appendix 3: New York Heart Association (NYHA) classification of cardiac (heart) involvement

<table>
<thead>
<tr>
<th>Stage</th>
<th>Criteria</th>
</tr>
</thead>
<tbody>
<tr>
<td>Class 1</td>
<td>No symptoms from ordinary activities</td>
</tr>
<tr>
<td>Class 2</td>
<td>Some symptoms from ordinary activities – comfortable at rest or with mild exertion</td>
</tr>
<tr>
<td>Class 3</td>
<td>Marked symptoms from ordinary activities – comfortable at rest only</td>
</tr>
<tr>
<td>Class 4</td>
<td>Confined to bed or chair, any activity causes discomfort</td>
</tr>
</tbody>
</table>
Useful organisations

**Carers UK**

0808 808 7777

Provides advice, information and support for carers.

**Citizens Advice**

England: 03444 111 444 Wales: 03444 77 20 20
Scotland: 0808 800 9060 Northern Ireland: call your local Bureau

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

**Mind**

0300 123 3393

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

**National Amyloidosis Centre (NAC)**

www.ucl.ac.uk/amyloidosis/nac

020 7433 2725

Based at the Royal Free and University College Medical School, London, the NAC is the only centre in the UK specialising in amyloidosis.

**NHS 111 Service**

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.
Myeloma UK is the only organisation in the UK dealing exclusively with myeloma.

With Myeloma UK you can...

Call the **Myeloma UK Infoline** for practical advice, emotional support and a listening ear:  
**UK:** 0800 980 3332  **Ireland:** 1800 937 773

Learn about AL amyloidosis from experts and meet others at our **Patient and Family AL amyloidosis Infodays**.

**Download** our information, which covers all aspects of AL amyloidosis - visit www.myeloma.org.uk

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

Visit [www.myeloma.org.uk](http://www.myeloma.org.uk), a one-stop-shop for information on AL amyloidosis; from news on the latest research and drug discovery to articles on support, treatment and care.

Watch **Myeloma TV** which hosts videos about AL amyloidosis presented by experts, patients and family members.

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

[www.myeloma.org.uk/amyloidosis](http://www.myeloma.org.uk/amyloidosis)
We need your help

Thanks to our generous supporters we are able to provide information and services 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 government funding. We rely on fundraising activities and donations.

You can support Myeloma UK by:

- **Making a donation**
  - Online at [www.myeloma.org.uk/donate](http://www.myeloma.org.uk/donate)
  - Over the phone **0131 557 3332**
  - Or by posting a cheque payable 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. 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

- **Leaving a legacy** – gifts from Wills are an important source of income for Myeloma UK and will 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 AL amyloidosis and investigate new treatments
Nobody ever forgets the moment they are diagnosed. 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 – Chairman, Myeloma UK
Notes
Myeloma UK thanks Dr Julian Gillmore and Dr Ashutosh Wechalekar for their invaluable help and advice in the compilation of this Essential Guide. HICKMAN® Catheter is a registered trade mark of C.R.Bard, Inc. All Myeloma UK publications are extensively reviewed by patients and healthcare professionals prior to publication.

To fill in a short survey about our patient information online, please go to www.myeloma.org.uk/pifeedback

If you’d like to give feedback specifically about this publication, please email myelomauk@myeloma.org.uk

For a list of references used to develop our resources, visit www.myeloma.org.uk/references
Myeloma UK Infoline: 0800 980 3332 or 1800 937 773 from Ireland
www.myeloma.org.uk

Myeloma Awareness Week 21 - 27 June