Autonomic neuropathy

Symptoms and complications of AL amyloidosis Infosheet

This Infosheet explains what autonomic neuropathy is and what causes it in AL amyloidosis patients. It also explains how it is treated and some tips for self-management.

What is autonomic neuropathy?

Neuropathy means 'damage to nerves'. Autonomic neuropathy means damage to the nerves of the autonomic system. These nerves control all of our bodily functions, such as heart rate and digestion.

What is the autonomic nervous system?

The nervous system controls our actions, our responses to information around us and the functioning of internal organs. It is made up of 2 parts:

- The brain and spinal cord – called the central nervous system
- The nerves around the body including the face, arms, legs and chest – called the peripheral nervous system

The autonomic nerves are a part of the peripheral nervous system. They control our internal organs and body processes without us being aware of it. This includes controlling internal processes such as:

- Blood pressure
- Heart rate
- Digestion
- Bladder function
- Sexual function
- Regulating body temperature

What causes autonomic neuropathy in AL amyloidosis?

AL amyloidosis causes an abnormal protein, called amyloid, to build up in the body. Amyloid can deposit in different tissues and organs including the autonomic nerves. Amyloid deposits forming around the autonomic nerves can damage them and interfere with the signals they send. This can disrupt the function of internal organs and bodily processes.

What are the symptoms of autonomic neuropathy?

The symptoms of autonomic neuropathy vary, and depend on which nerves are affected. Early symptoms can include dizziness when standing and nausea or vomiting when eating.

The symptoms of further nerve damage will depend on the extent of the damage and the nerves affected. Autonomic neuropathy can affect the function of particular organs and systems of the body, for example:

- Digestive tract – constipation, diarrhoea, feeling of fullness after eating small amounts of food, nausea (particularly after eating), vomiting
- Bladder – frequent urinary tract infections (UTI's), difficulty emptying bladder, incontinence
- Heart – low blood pressure, dizziness, fainting, exercise intolerance
- Genitals – erectile dysfunction, vaginal dryness
- Body temperature control – sweating too much or too little

The symptoms you experience, and how severe they are, will depend on where the nerve damage has occurred.

People with autonomic neuropathy may also have some symptoms of peripheral neuropathy. This is where the nerves controlling sensation are damaged. Peripheral neuropathy causes symptoms such as pain, numbness or tingling in the hands and feet.

For more information, see the **Peripheral neuropathy (AL amyloidosis) Infosheet** from Myeloma UK

How is autonomic neuropathy assessed?

You will be asked about your symptoms and may have tests to check your body functions. These tests may look at:

- How your blood pressure changes as you move from lying to sitting and standing
- How well your bladder is storing and releasing urine
- How slowly you digest food or empty your stomach

What are the treatments for autonomic neuropathy?

Treatment for autonomic neuropathy is focused on treating your AL amyloidosis. This will control amyloid deposits and prevent further damage to the nerves.

Nerve damage that has already occurred cannot usually be reversed. Existing symptoms are managed to improve your quality of life.

Digestive symptoms

If you are experiencing problems with digestion, you may be referred to a dietitian to help make changes to your diet. You can also be prescribed treatment by your healthcare team if symptoms persist.

Heart symptoms

Symptoms related to heart rhythm and blood pressure can usually be controlled with treatment prescribed by your healthcare team.

Sexual dysfunction symptoms

Sexual dysfunction can be treated in a variety of ways, for example with erectile dysfunction treatments or vaginal lubricants.

Many people find it an embarrassing topic to discuss with their healthcare team. Be assured that they are used to having these conversations. You should speak to your healthcare team before taking any over the counter treatment for sexual dysfunction.

Tips for self-management

There are different things you can do to make living with autonomic neuropathy easier. Depending on your symptoms, the following tips may help:

- Drink fluids – if you have diarrhoea you should drink fluids to replace those you have lost. However, AL amyloidosis patients are at risk of fluid overload and usually need to limit their intake. Speak to your healthcare team to determine how much fluid you should drink
- Take your time when standing up – this can help with dizziness. Try standing up in stages, for example go from lying down to sitting on the side of the bed for 30 seconds, then hold on to something for 30 seconds when you stand up, before walking
- If you are sitting or lying down for a long period of time, tense your muscles regularly to increase blood flow
- Raise the head end of your bed – if you have circulation problems, sleeping with the head of your bed raised can help. Try using bricks or large books under the head end of the bed to raise it by a few inches
- Gentle exercise may help, but ask your healthcare team for advice before starting any new exercise routine, to make sure it is suitable for you
- Avoid excessive heat such as hot tubs if you have symptoms of dizziness
- Ask for a referral to a dietitian if you have problems with your digestive system. They can offer dietary advice and suggestions, such as eating smaller meals more often
- Get support – autonomic neuropathy symptoms can have a psychological impact, and talking to others can help

For more information on support for people with AL amyloidosis see the **AL amyloidosis Essential Guide** from Myeloma UK

Key points

- Autonomic neuropathy is damage to the nerves that control bodily functions
- It occurs when the abnormal amyloid protein deposits on the autonomic nerves and interferes with the signals these nerves send
- Symptoms vary but can include digestive problems, bladder problems, dizziness, or problems with sexual function
- Treatment involves preventing further nerve damage by controlling the underlying AL amyloidosis, and managing symptoms caused by damage that has already occurred
- There are a number of ways to make living with autonomic neuropathy easier

Notes

About this Infosheet

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

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

We value your feedback about our patient information. For a short online survey go to **myeloma.org.uk/pifeedback** or email comments to **patientinfo@myeloma.org.uk**

Other information available from Myeloma UK

Myeloma UK has a range of information booklets available covering all aspects of AL amyloidosis, its treatment and management. Download or order them from **myeloma.org.uk/publications**

To talk to one of our Information Specialists about any aspect of AL amyloidosis, call the Myeloma UK Infoline on **0800 980 3332** or **1800 937 773** from Ireland.

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

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

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MyelomaUK

We're here for everything a diagnosis AL amyloidosis brings

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

Call the Myeloma UK Infoline on
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