AL amyloidosis and autonomic neuropathy

This Infosheet explains what autonomic neuropathy is, what causes it in AL amyloidosis patients, what its symptoms are, how it is treated and some tips for self-management.

What is autonomic neuropathy?
Autonomic neuropathy is the term used to describe damage to the nerves that make up the autonomic nervous system.

What is the autonomic nervous system?
The autonomic nervous system is part of the peripheral nervous system (the part of the nervous system that consists of the nerves outside the brain and spinal cord). It is responsible for automatically (autonomously) regulating processes in the body that are not controlled by conscious effort. This includes controlling internal processes such as:
- Blood pressure
- Heart rate
- Digestion
- Bladder function
Sexual function

For more information about the peripheral nervous system and peripheral neuropathy see the Peripheral neuropathy Infosheet from Myeloma UK

What causes autonomic neuropathy in AL amyloidosis?
The abnormal amyloid protein that is produced in AL amyloidosis can deposit in various tissues and organs including the autonomic nervous system. Amyloid deposits forming around nerves can damage them and interfere with the information sent along them between the brain and the organs of the autonomic nervous system. This causes their function to be impaired and causes symptoms.

What are the symptoms of autonomic neuropathy?
The symptoms of autonomic neuropathy depend on the nerves affected. Early symptoms can include dizziness when standing and nausea and/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 small amounts of food, nausea (particularly after eating), vomiting
- Bladder – frequent urinary tract infections, incontinence, urinary retention (inability to empty your bladder)
- Heart – low blood pressure, dizziness, fainting, exercise intolerance, heart attacks
- Genitals – erectile dysfunction, vaginal dryness

What are the treatments for autonomic neuropathy?
Nerve damage is irreversible but the symptoms of autonomic neuropathy can be managed to improve quality of life. To prevent further autonomic neuropathy occurring, the underlying AL amyloidosis is treated while existing symptoms are controlled.

Complimentary therapies, such as acupuncture and transcutaneous electrical nerve stimulation (TENS), may help to relieve some of your symptoms.

Digestive symptoms
If you are experiencing problems with digestion you may be advised to make small changes to your diet to help prevent constipation or diarrhoea. You can also be
prescribed treatment by your doctor if symptoms persist.

**Heart symptoms**
Symptoms related to heart rhythm and blood pressure can usually be controlled with treatment prescribed by your doctor.

**Sexual dysfunction symptoms**
Sexual dysfunction can be treated in a variety of ways, for example with erectile dysfunction drugs or vaginal lubricants. It can be a difficult and embarrassing topic to discuss with your doctor or nurse, but they are there to help you with all symptoms and side effects and will be used to talking about it. You should speak to your doctor before taking any over-the-counter treatment for sexual dysfunction.

**Tips for self-management**
There are some lifestyle adjustments that can make living with autonomic neuropathy easier, including:

- Drinking plenty of fluids – if you have diarrhoea you should drink lots of fluids to replace those you have lost
- Posture changes – taking your time when standing up, such as standing in stages, can decrease dizziness. If you’re sitting or lying down for a long period of time,
- Tense your muscles regularly to increase blood flow
- Elevating your bed – if you have low blood pressure you may benefit from elevating the head of your bed

**Summary**
Autonomic neuropathy is a group of symptoms that can, if left untreated, worsen and affect your quality of life. It is important that you are aware of any symptoms and report them to your doctor or nurse as soon as possible.

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

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

To give feedback about this publication, email [myelomauk@myeloma.org.uk](mailto:myelomauk@myeloma.org.uk)
Other information available from Myeloma UK

Myeloma UK has a range of publications covering all aspects of AL amyloidosis, its treatment and management. To download any of these publications go to www.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 www.myeloma.org.uk/amyloidosis
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Myeloma Awareness Week 21 - 27 June