

Mouth care

This Infosheet explains the causes of mouth problems in AL amyloidosis patients, what to look out for, treatments available and tips for self-management.

Good mouth care is always important to help ensure your mouth is kept clean, moist and free from infection. When you have AL amyloidosis it is essential to be extra vigilant with your mouth care as you may be more prone to a variety of problems including a sore or inflamed mouth, infections, bleeding gums and a dry mouth.

What are the causes of mouth problems?

Amyloidosis itself

Amyloidosis may directly affect the tongue, causing enlargement and tenderness. This is known as macroglossia, and may cause difficulty in eating or talking. There is no specific treatment for macroglossia but successful treatment of the underlying disease may lead to an improvement.

Amyloid deposits in the tongue are often slower to clear up than those in other parts of the body.

Weakened immune system

When you have AL amyloidosis you are likely to have a weakened immune system. This can mean that you are at an increased risk of picking up infections. Common mouth infections include the fungal infection known as thrush (or candidosis) and the viral infection herpes simplex which often results in cold sores.

Treatment side-effects

Some of the chemotherapy drugs used in the treatment of AL amyloidosis can cause a variety of mouth problems, especially inflammation or ulceration of the lining of the mouth known as oral mucositis.

This occurs when chemotherapy attacks the rapidly dividing cells in the body, such as those in the lining of the mouth. Oral mucositis can be extremely painful and can make eating and drinking very difficult, especially after high-dose therapy and stem cell transplantation (HDT-SCT).

Some AL amyloidosis treatments can temporarily lower your platelet count. Platelets are the blood cells which play an important role in blood clotting.

As a result of a lowered platelet count you may notice that you bleed more easily – especially from your gums or the corner of your mouth. This can sometimes lead to painful cracks around your mouth.

Another common side-effect of treatment is a dry mouth as some AL amyloidosis treatments can interfere with saliva production. Although this can be unpleasant and uncomfortable, it is worth remembering that most mouth problems are usually a temporary and can be treated.

Signs and symptoms

It is a good idea to get into the habit of inspecting your mouth every day so that you can detect any visible changes. To do this you will need to look closely at your gums, your tongue and the lining of your mouth.

Let your doctor or nurse know if you are experiencing any of the following:

- Unusual dryness of the mouth
- Redness or swelling of the tongue, lips, gums or the lining of the mouth
- Gums that bleed easily or are inflamed

- Sores on the lips or at the corners of the mouth
- Mouth ulcers
- Altered taste or sensation in mouth
- White plaques coating the tongue and the lining of the mouth
- Pain or numbness in the jaw or surrounding area
- Loose or damaged teeth

Treatments available

It is important to inform your doctor, or nurse, as soon as you notice any changes to your mouth so that the appropriate treatment can then be prescribed. Treatments may include:

- Antibacterial mouthwash (e.g. chlorhexidine) – to reduce the risk of infection
- Anaesthetic mouthwash (e.g. difflam) – to relieve pain
- Antiviral medication (e.g. acyclovir, Zovirax™) – to treat, or prevent, cold sores
- Antifungal lozenges, drops or mouthwash (e.g. nystatin) – to treat and prevent oral thrush
- Artificial saliva spray (e.g. glandosane) – to help relieve the discomfort of a dry mouth

- Pain-killers (e.g. codeine or morphine) may sometimes be required (often in a liquid form or via a syringe driver) for severe mucositis

Some treatments are given as a preventative measure against mucositis before starting HDT-SCT. These include:

- Caphasol – a mouth rinse that moistens and cleans the mouth helping to prevent and treat mucositis.
- Palfermin – a type of medication which helps to stop sores forming and encourages any ulcers to heal faster.

Try to get into a good routine with your mouth care and ensure that you take any treatment that your doctor has given you. If your mouth is sore, try taking pain-killers or an anaesthetic mouthwash before you eat.

If you need any invasive dental treatment, it is important that your dentist knows about your AL amyloidosis and any treatment that you are receiving. It is also advisable to discuss any proposed dental treatment with your doctor prior to undergoing the procedure.

Tips for self-management

- Try to keep your mouth clean by brushing your teeth at least twice a day. Use a soft toothbrush and only brush very gently around your gums
- Avoid flossing your teeth unless you know that your platelet count is normal
- Keep your mouth moist and fresh and try to drink plenty of clear fluids
- Use vaseline or lip balm to help keep your lips moist
- Keep your dentures clean and remove them at night
- Visit your dentist regularly, especially prior to the start of any new treatment
- Avoid smoking, and only drink alcohol in moderation
- Inspect your mouth daily and inform your doctor or nurse of any changes
- Avoid alcohol and tobacco as they too can irritate your mouth
- Eat soft or puréed foods or moisten foods with gravy, melted butter or sauces to make them easier to chew
- Try to keep drinking – use a straw if necessary
- Eat ice cubes or ice lollies – they can soothe a sore mouth and help with dryness
- Avoid wearing dentures for a while if your mouth is very sore or inflamed
- Ask to be referred to a dietician if you are having problems eating – they can prescribe supplements to boost your nutritional intake
- Use mouthwashes regularly as they can provide temporary relief

Coping with a sore, dry or infected mouth

- Take pain-killers regularly throughout the day, or as prescribed – do not wait until you are in pain
- Avoid spicy, acidic or salty foods as they can increase irritation in your mouth

In summary

It is recognised that a sore mouth (oral mucositis), if left untreated can impact on your quality of life. In order to prevent it becoming a problem it is important to try to adopt some of the self-management strategies outlined in this Infosheet.

There is now an increased awareness of the mouth care needs of AL amyloidosis patients.

Research is ongoing to try to establish the most effective mouth care regime – particularly during high-dose therapy and after stem cell transplantation.

About this Infosheet

The information in this Infosheet is not meant to replace the advice of your medical team. They are the people to ask if you have questions about your individual situation. All Myeloma UK publications are extensively reviewed by patients and healthcare professionals prior to publication.

Other information available from Myeloma UK

Myeloma UK provides a wide range of information covering all aspects of the treatment and management of AL amyloidosis.

For a full publication list visit www.myeloma.org.uk/publications

To order your free copies contact Myeloma UK. Our information is also available to download at www.myeloma.org.uk

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

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

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