



KIDNEY CANCER SUPPORT NETWORK

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Martin's Help Sheet TREATMENT/TKI SIDE EFFECTS ON THE MOUTH

Many patients with secondary kidney cancer are initially put on drugs called Tyrosine Kinase Inhibitors (TKIs) such as sunitinib (Sutent) or pazopanib (Votrient). Whilst these drugs are generally very effective, unfortunately many patients suffer some side effects to a greater or lesser degree, one of which is the impact on the mouth. Have a look here at the drug manufacturer's website:

<http://www.sutent.com/possible-side-effects>

The most common side effects reported by members of the KCSN are:

- Dry mouth
- Sore mouth/increased sensitivity
- Mouth ulcers
- Taste changes
- Difficulty swallowing

These reactions are caused by mucositis, which is an inflammatory reaction of any or all of the mucous linings of the upper gastrointestinal tract from mouth to stomach (including mouth, lips, throat) and surrounding soft tissues. Inflammation in the mouth is called stomatitis and inflammation of oesophagus is called oesophagitis.

<http://www.macmillan.org.uk/information-and-support/coping/side-effects-and-symptoms/mouth-problems>

Unfortunately, there is no drug available that can stop these symptoms, so it's all about providing relief from the discomfort, until hopefully symptoms decrease. This help sheet gives a list of remedies that have been found effective by members of the Network. The extent to which patients get the symptoms can vary greatly, so there is no guarantee that what worked for one patient will work for you, but hopefully by capturing all the remedies below, new members can find something that works for them. Another important fact to bear in mind when starting on TKIs is that many members have reported that the side effects do reduce over time, probably as a result of the body becoming more tolerant, so if you are finding it hard going to begin with, hang in there as things may improve.

Dry mouth

The following have been found beneficial for those suffering from a dry mouth:

Glandosane: is a saliva replacement spray and is available on prescription

BioXtra gel available online

Glycerin throat pastilles are also good for the dry mouth problems

Biotene gel: available from Boots.

Sore mouth

Often patients suffer from a sore mouth, which generally entails heightened sensitivity to such things as hot drinks, spicy or acidic food and toothpaste. The following are suggestions from group members to help with a sore mouth:

Avoid: sounds obvious, but avoid anything that will cause pain such as spicy or acidic food such as citric juices (tomatoes, oranges, lemon, etc.) and sauces and dressings containing vinegar. Often tolerance to heat is also reduced, so it's not even possible to enjoy a hot cup of tea and coffee! Adding an ice cube may lower the temperature to a level that can be tolerated. Drinks and liquid medication containing alcohol (i.e. some cough medicine) if not essential, are best avoided - how much do you want that beer? Even drinking carbonated drinks can be unpleasant, although drinking through a straw may help.

The same applies to hot food, and unfortunately the time between it being cool enough to eat and becoming cold and unappetising can be all too short. To keep up intake (which is essential) either eat cold food or eat more often. Also some harder foods like biscuits can be quite "scratchy" in the mouth and hence uncomfortable to eat. Some members found Farley's Rusks great as they melt in the mouth and taste good (apparently!) Also watch out for too much fruit because of the acidity of some fruits.

Diffiam Oral Rinse: works by numbing the mouth, and is available on prescription. However, for some it can be painful itself, but some have diluted it with some water and some found it to be effective.

Gelclair is a concentrated oral rinse gel, made by Cambridge Laboratories and distributed in UK by Alliance Pharmaceuticals. It's a gel in a sachet that you dilute in water and gargle. Some members found it to be beneficial to use before eating to coat the mouth before eating. Some found the taste unpleasant. It may be possible to get on prescription.

Manuka honey: Some people find manuka honey helps, take a spoonful – can also be rubbed on mouth sores directly. There are different grades available 5+, 10+, 15+ in increasing expense, please let us know which works best .

Corsodyl alcohol free mouthwash: rinse the mouth with the mouthwash as often as possible. Can be diluted. Available on prescription.

Ice: Some found sucking ice lollies or ice cubes gave some relief and pleasure (in the case of lollies!) This also helps with hydration.

Bicarbonate of Soda: Some used this diluted in water as a mouth wash.

Gengigel Gingival Gel: (try saying that!). Some found this gel worked well. Its available from any good health food store, Boots chemist or online

MuGard Oral Mucoadhesive: an oral wound rinse that is rinsed around the mouth and reduces sensitivity. Available online: <http://www.mugard.com>

Salt water mouthwashes: cheap, but some found them very effective. Dissolve some sea salt in warm water - swill round and spit out

Frozen pineapple pieces: are said to be very good, soothing and healthy

Dissolvable aspirin mouthwashes - swill round, gargle in your throat if sore then spit out

Magic Mouthwash: is the name of a mixture prepared by a pharmacist using doctor's specifications (there can be additions depending on the patient's particular problems, like thrush for example). Pharmacists can make it for you if your doc will write the prescription. The basic mixture is 1/3 Maalox (so it sticks to the mouth lining), 1/3 Lidocaine (local anesthetic), and 1/3 Benedryl (eases irritation). Swish for 30 seconds to one minute and spit, or if the throat is also irritated, the product can be swallowed

Mouth ulcers

Unfortunately it is also quite common to get mouth ulcers, particularly in the early stages of treatment, which can be a nuisance. Firstly check your toothpaste, as some have found SLS to be a leading cause of mouth ulcers and chronic inflammation of the cheek and tongue. So if yours has SLS, it may be time to change. See the section on toothpastes below. Here's some suggestions from members for helping with mouth ulcers:

Lysine: found in health food shops really helped. It may take a while to take effect.

Liquorice: is supposed to help with mouth ulcers. If you don't like traditional liquorice, there is the flavoured Australian variety. Beware it can be addictive, and too much can have you running to the loo, as it is also a remedy for constipation- eat in moderation.

Bonjela. Traditional treatment, available from chemists. Numbs the area,

Orajel: was also recommended. It also numbs the area.

Aloclair Plus: Found by some members to give fast relief & healing for mouth ulcers

Nystatin: a prescription preparation for oral thrush, but members report good relief from mouth ulcers.

Taste changes

Unfortunately TKIs can cause changes to the taste buds, and for some things lose their taste, or have a metallic taste. For many this is a phase that tends to pass, but it can be tough forcing yourself to eat when there is no pleasure in it and everything tastes the same.

There are no specific remedies for this, but one thing to be aware of – using aluminium saucepans can heighten the metallic taste, so best to avoid if you can.

Swallowing

It is quite common to experience some difficulty in swallowing when on TKIs, and for some this can be linked to incidences of reflux. Many of remedies listed above in the "Sore Mouth" section will assist with this. but if it becomes a real issue and is stopping you eating sufficient, speak to your oncologist about trying a:

Proton Pump Inhibitor: a tablet such as Omeprazole. This once a day tablet has completely fixed swallowing issues for some.

Toothbrushes

Just one piece of advice here - whether you use electric or manual, get a super soft toothbrush, or better still get a baby's toothbrush as it's much kinder.

Toothpaste

When the mouth is sore, using traditional toothpaste can be very painful - the reason being they contain Sodium Lauryl Sulfate (SLS), which is the foaming agent. SLS is used as a degreaser in garage floor

cleaners, car wash soaps and many industrial cleaners. (enough said!). It strips the skin of its natural protective layers. So if you are having a burning tongue sensation or ulcerations that are irritated after brushing your teeth, check your toothpaste, and if it contains SLS, it's time to change. Below is list of alternative toothpastes that members found worked for them:

Childrens toothpaste: readily available and cheap – check ingredients although because it may still contain SLS. They will however, contain less fluoride, so are not as good for long term use.

Sarakan: A natural toothpaste, made from extracts from the Toothbrush Tree – yes there is such a thing! Available online and at good health food shops

Aloe vera toothpaste: available in health food shops

Kingfisher fluoride free toothpaste: available online and at good health food shops

Biotene toothpaste: Primarily for those with a dry mouth, but was found by some to be tolerable. It is available at Boots, but is quite expensive. However some have got it on prescription.

Mouthwash

The general advice is to avoid mouthwashes containing alcohol. Here are a couple of recommended ones:

Biotene Mouthwash: quite pricey, but can be got on prescription. Available at Boots

Sarakan Mouthwash: Natural mouthwash available online at a reasonable price and at good health food shops.

Please help other patients:

Please keep us updated with useful information that will help other cancer patients. You can email us with your tips so we can regularly add to this resource. Please email us at: team@kcsn.org.uk or visit our website www.kcsn.org.uk.

Thanks to all the KCSN members for their input, and especially to Martin for his patience and willingness to collate this information to help and support others.

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