

Common Symptoms in Patients with Kidney Disease:

Helping Yourself to Feel Better

Contents: Dry Mouth and Thirst; Poor Appetite, Nausea and Vomiting; Itch and Dry Skin; Constipation; Restless Leg Syndrome; Difficulty Sleeping; Depression, Anxiety and Worry; Fatigue; Pain; Coping with Symptoms

Introduction

People with kidney disease, including those on dialysis, can be troubled by a range of symptoms. Some people have very few symptoms, others have lots. The symptoms may be very mild or they may be severe. They may come and go or be there all the time. Everyone is different.

This guide lists some of the most common symptoms that people with kidney disease may (or may not) have, and describes ‘things you can try at home’ to help make these symptoms better. If one suggestion doesn’t work, try another, or try several together. Importantly, if you do have any symptoms, as well as trying the suggestions listed in this guide, it is important to let your doctor know, as there may be other things they can do to help.

Dry Mouth and Thirst	3
Poor Appetite, Nausea and Vomiting	4
Itch and Dry Skin	6
Constipation	7
Restless Leg Syndrome	9
Difficulty Sleeping	9
Depression, Anxiety and Worrying	11
Fatigue	11
Pain	13
Coping With Symptoms	13

Dry mouth and Thirst

Having a dry mouth and feeling thirsty are common problems in patients with kidney disease, who may need to limit how much they drink. Many patients find it hard not to drink more than they should because they feel so thirsty.

The most important way to feel less thirsty is to eat less salt. Eating salt makes you thirsty. The more salt you eat, the thirstier you become. Anyone who eats a lot of salt will find it very difficult to limit how much they drink. Many patients complain that having less salt in their food makes their food less tasty. However, if you keep eating less salt your taste will gradually change – you will find that food becomes tasty again without needing to add salt.

Things you can try to help with dry mouth and thirst are:

- **AVOID SALT**
 - Do not add salt to food or while cooking; try using spices or herbs instead for flavouring
 - Avoid take-aways, snacks and processed foods, which are often very high in salt.
 - Check food labels - low salt foods contain less than 120mg/100g
 - Speak to a dietitian
- Avoid sugary foods, alcohol, tobacco and caffeine, which all dry the mouth
- Rinse and spit out water, or just take small sips
- Adding a few drops of lemon juice to water can help your mouth to produce more saliva
- Sucking on ice instead of having a drink
- Chewing gum

- A humidifier in the bedroom can help symptoms of dry mouth at night
- Saliva substitute, eg Biotene, is available over the counter at the pharmacy

Bad smells and tastes in the mouth are also sometimes a problem for patients with advanced kidney disease. Tooth or gum disease can also cause these symptoms – regular tooth brushing, flossing and dental check-ups are advised.

Things you can try to help with bad smells and tastes are:

- Increasing the flow of saliva in your mouth
 - Try chewing gum or adding a few drops of lemon juice to water
- Avoid a dry mouth (see above)
- Mouthwash - but don't use any mouthwash which contains alcohol as this can worsen dry-mouth; check products with your pharmacist.
- A bad taste in the mouth can sometimes be caused by too little dialysis – discuss this with your doctor.

Poor Appetite, Nausea and Vomiting

Poor appetite, nausea (feeling like you are going to vomit) and vomiting can be caused by a build up of toxins (poisons) in the body that are usually removed by the kidneys, or can be due to other medical problems or side effects from medications. It is important that causes are identified and treated – talk to your doctor or nurse. Starting dialysis or doing more dialysis may help with these symptoms.

Things you can try to help with these symptoms are:

- Avoid a dry mouth and/or a bad taste in the mouth– see the section above
- Eating smaller meals more often may be easier than trying to eat larger meals.
- Eating in the company of other people can help
- Many different medicines can cause an upset tummy. Taking medicines with food may help prevent this, but it is important to check with your doctor or pharmacist which medicines need to be taken on an empty stomach.
- If you think a particular medicine is causing nausea or vomiting then discuss changing it with your doctor.
- Ask to see a dietitian
 - If you are eating less than normal, there is a risk you could become malnourished. Dietitians can develop a plan with you to help you get enough energy and vitamins from the foods you are able to eat.

NOTE: There are many different causes of vomiting. Sometimes vomiting is caused by a serious illness. If vomiting is a new symptom for you, or if it is getting worse, then you should see a doctor (e.g. your GP or kidney doctor) as soon as possible to work out the cause. If you have pain in the tummy with vomiting, or you keep vomiting and are not able to eat or drink then you should go to your local emergency department as soon as possible.

Itch and Dry skin

Itch is a very common symptom in patients with kidney disease. It is thought to be caused by a build-up of toxins (poisons) that are usually removed by the kidneys. Itch is often helped by starting dialysis. For patients already on dialysis, it can sometimes be helped by increasing the amount of dialysis you do – talk to your doctor about this. High levels of certain chemicals in the blood, including phosphate, may make itch worse. Controlling the amount of phosphate in your diet and taking phosphate-binder drugs may help. If you are not sure which foods you should and shouldn't eat then ask to speak to a dietitian.

Dry skin is very common in patients with kidney disease and can make itch worse. Dry skin and itch can be helped by the following:

- Use an emollient/moisturiser (eg. sorbolene) to keep skin moist
 - Apply generously, 2-8 times daily as required to keep skin moist.
 - After bathing, gently dry your skin and then apply moisturiser.
- Do not use soaps as they dry the skin – use a soap substitute eg. cetaphil or QV
- Do not use very hot water
- Do not spend a long time in the bath or shower
- Wash and dry your skin gently
- Do not use any products which contain alcohol on your skin (check the label, or ask your pharmacist)
- Wear loose, cotton clothing; avoid synthetic fibres like polyester
- Do not scratch
- Keep your nails short in case you scratch in bed at night
- Some people find caffeine, alcohol and spicy foods can worsen itch – try avoiding these and see if your symptoms improve

Other treatments you could try, which have been reported to help in some patients are:

- Evening primrose oil. Take one tablet twice daily.
 - Available from the pharmacy without a prescription
- Capsaicin cream applied to the itchy area as required (up to 4 times daily)
 - Available from the pharmacy without a prescription
 - Note: it may cause a burning or stinging sensation when first used, but this usually stops after a few days of use

If itch is still a problem, talk to your doctor about other medications such as antihistamines or gabapentin.

Constipation

Constipation means passing stools (doing a poo) less often than normal, or having to really push to pass hard stools. It is a common problem in patients with kidney disease. It is important that constipation is treated early to prevent it getting worse. Constipation in patients on peritoneal dialysis can lead to problems with how fluid drains from the catheter.

An important step in treating constipation is to have your diet and medications reviewed by your doctor and dietitian. Some medications - such as phosphate binders, iron tablets and some pain-killers - can cause constipation. Your doctor may be able to change your medications if they are thought to be making constipation worse. Often patients with kidney disease have been told to avoid certain foods that contain a lot of potassium or phosphate. A dietitian can advise on ways to safely increase the amount of fibre in your diet to make constipation better, without having too much potassium or phosphate.

Regular exercise is good for the bowels (as well as the heart, mind, bones and muscles!)

Many patients with constipation will need treatment with medications. Some medications available in the pharmacy are not safe for some patients with kidney disease. For example, **you should not start medicinal fibre (Psyllium or Metamucil) without talking to your doctor** as you need to drink a large amount of fluid for it to work.

Things you can try are:

- Coloxyl and Senna tablets
 - Available over the counter at the pharmacy
 - Start at a dose of two tablets once daily
 - You can increase to 2 tablets twice a day if you need to
 - Useful for occasional or short-term use; if requiring for more than 2 weeks then see your doctor
- Lactulose
 - Available over the counter at the pharmacy
 - Start at 10ml twice daily
 - You can increase to 20ml twice daily if you need to
 - Safe for regular, long-term use

If you need to start medications for constipation you should also see your doctor as further investigation or changes to your medications may be needed.

NOTE: If you are experiencing tummy pain or vomiting with constipation you should see a doctor urgently.

Restless Leg Syndrome

Restless leg syndrome is a condition where patients develop uncomfortable feelings in the legs that only get better when they move their legs. It is quite common in patients with kidney disease, particularly in those on dialysis. Things you can do to help are:

- Avoid caffeine, alcohol and nicotine, which can make symptoms worse
- Massage your legs (or ask someone else to!)
- Warm baths or heating pads
- Keeping mentally active when you are resting or bored
- Exercise during the day (but not within 4 hours of bed-time)

If your symptoms are bad enough to need medications there are several that can help – discuss these with your doctor.

Difficulty Sleeping

Lots of people have difficulty getting a good night's sleep. For some people, poor sleep may be due to problems such as anxiety/depression, restless leg syndrome or alarms from dialysis machines. Working out the causes of bad sleep is important as treating the cause may improve your sleep – discuss this with your doctor or nurse.

Poor sleep can often be made worse by bad habits. There are a list of rules you can follow – known as 'sleep hygiene' - to try and improve sleep. It is best to try and follow as many of these rules as possible.

Further information can be found at:

http://www.betterhealth.vic.gov.au/bhcv2/bhcarticles.nsf/pages/Sleep_hygiene

Sleep Hygiene 'Rules':

- Only go to bed when you feel tired.
- Sleep only as much as you need to feel rested and then get out of bed
- Get up at the same time every morning, including weekends. Use an alarm if you need to.
- If you are unable to fall asleep within 20-30 minutes, get out of bed and go to another room. Read a book. Only go back to bed when you feel sleepy. Repeat this step as many times as you need to throughout the night.
- Only use your bed for sleep and sex. Do not watch TV, read, eat, or worry while in bed.
- Make sure your bed and bedroom are comfortable and cosy
 - Sleep on a comfortable mattress
 - Make sure you aren't too hot or cold
 - Make sure the room is dark enough
 - If noise is a problem, ear plugs can really help (but shouldn't be used if you're dialyzing overnight!)
- Exercise regularly, more than 5 hours before bedtime
- Avoid caffeine (coffee, tea, coca-cola) after lunch and avoid alcohol and cigarettes in the evening
- Do not go to bed hungry
- Deal with your worries before bedtime
- If your mind is racing in bed, try the following relaxation exercise:
 - Lie on your back with your eyes closed. Take some slow deep breaths in and out. Begin by clenching your toes and slowly count to ten, then relax and count to ten. Now repeat this exercise moving up through muscle groups in your body – lower legs, upper legs, buttocks, abdomen, chest, fingers, forearms, upper arms, shoulders, neck, face and scalp.

Depression, Anxiety and Worrying

Anxiety and depression are very common conditions. If you are struggling emotionally, then tell your treating team - we are here to help. Remember that everyone goes through difficult times in their lives and everyone needs to ask for help from time to time. Also be reassured that anxiety and depression are usually temporary conditions – you won't always feel like this!

Some people worry a lot about their health problems. Sometimes worrying can get out of control and make it hard for people to think about anything else or get on with their lives. When this happens psychologists can teach people techniques to help break the worry-cycle and help get them back on track. If you think your worrying is getting out of hand, discuss this with your doctor.

Fatigue

Fatigue (feeling tired) is one of the most common symptoms in patients with kidney disease. Many patients may have only mild fatigue, while some find they feel worn out a lot of the time. There are lots of causes and it is important that your doctor identifies any causes that can be treated. Sometimes medications can make fatigue worse – your doctor can look at your list and see if any changes can be made to try and make you feel better.

Fatigue may be caused by a build-up of toxins (poisons) that are usually removed by the kidneys. Starting dialysis or increasing the amount of dialysis you do may help with fatigue. Anaemia (a low level of blood in the body) is common in patients with kidney disease and may be a cause of fatigue. If your blood count is low your doctor may prescribe you a medicine called erythropoietin (EPO). This helps the body produce more blood, which can help with fatigue.

Some patients find fatigue is worse after dialysis. Sometimes this is caused by removing a lot of fluid on dialysis. Making sure you don't drink too much between dialysis sessions can help with this (see dry mouth and thirst above). Sometimes your doctor may suggest doing more or less dialysis to help with these symptoms.

Poor sleep, pain, anxiety and depression can all make fatigue worse. See the sections above and discuss with your doctor.

Some general tips for helping with fatigue are:

- Eat a healthy diet
- Eat breakfast and don't miss any meals
- Gradually increase the amount of exercise you do
- Avoid long periods of doing nothing
- Avoid too much caffeine – not more than one or two caffeinated drinks per day (eg coffee, tea)
- Reduce stress
- Organise your day's activities around the times you have most energy

Pain

The best treatment for pain is treating the cause if possible. If you are suffering from pain be sure to tell your doctor. It is very important to tell your doctor about any new pain you have, as it may need investigations to find out what's causing it.

Paracetamol is safe to use in patients with kidney disease and those on dialysis so long you do not take more than the recommended dose. Paracetamol tablets come in different strengths, so check the packet for details on how many you can take and how often.

Certain pain killers, called NSAIDs, can be unsafe in patients with kidney disease. These drugs include ibuprofen, diclofenac, meloxicam, indomethacin and naproxen, but there are lots of others. **Check any new pain killer with your pharmacist and do not start one of these drugs without first discussing it with your doctor.**

Coping with Symptoms

Your medical team will try to make any symptoms you have better, but unfortunately it is not always possible to make all symptoms go away. Some patients find dealing with symptoms every day to be very difficult, and can become angry and frustrated. This can make symptoms feel even worse. Learning to cope with symptoms being there can help make both the symptoms and the mental burden better.

Some things you can try to help are:

- Reduce stress. Everything seems worse when you are stressed. Set aside time to relax. Eat well and get enough sleep. Exercise regularly.
- Try to think positively and try to avoid focusing on the symptoms being there. Instead try to think about what's good in your life and focus on the fact that you are working towards getting better in a healthy way.
- Do something you enjoy to help distract you from the presence of symptoms and give you something positive to focus on.
- Avoid spending time alone just thinking about your symptoms.
- Find support: dealing with problems alone can be very tough. Talk to your loved ones and your medical team about what you're going through. Talking to others who have similar problems can help. Kidney Health Australia co-ordinates 'Kidney Clubs' across Australia for people with all stages of kidney disease (for more information see: <http://www.kidney.org.au/ForPatients/KidneyClubs/tabid/615/Default.aspx>).
- Some people find that meditation or yoga help them feel better both physically and mentally. If you are planning to try yoga discuss with your doctor if there are any movements or poses you should avoid.
- Ask for help: if you are struggling to cope with your symptoms then tell your doctor; you may benefit from speaking with a psychologist.

Feedback

To help improve this guide in the future, if you have any comments about the contents of the booklet, positive or negative, or have found anything particularly useful, I'd love to hear from you:

Please address correspondence to:

Dr Matthew Davies, 195 Specialist Centre, 195 Thompson's Road, Bulleen, VIC 3105

Or email: matthew.davies@austin.org.au

Produced by:

- Dr Matthew Davies, Nephrologist, with assistance from the medical, nursing and allied health staff of the Austin Health Nephrology Department, and Dr Juli Moran & Dr Sarah Charlton from Austin Health Palliative Care Department.