



Common medications

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The following is a brief guide to a few of the medications you may be prescribed. Medications are prescribed depending on the need of the individual therefore you should not be alarmed if you are not on all of these. Equally you may be prescribed additional medications that are not listed. When you are prescribed a new medication we encourage you to discuss why you need the medication and its side effects with your hospital team.

Do not be alarmed when reading the side effects. Medications can affect people differently and it's rare that anybody experiences all of the side effects. It may be that you only experience one or two mild effects, or you may not even experience any at all.

Cystinosis specific medication

Medication: Cysteamine

Brand names: Cystagon® (white capsule)

Why do I need it? Cysteamine severely reduces the amount of cystine within the cells. If started early enough delay the progression of kidney failure and reduce the damage done to other organs.

Possible side effects: Side effects include vomiting, nausea, diarrhoea, lethargy, skin odour and breath odour. If you would like to know more about the side effects please discuss this with a healthcare professional.

Medication: Cysteamine eye drops

Brand names: Available in varying strengths – 0.55%, 0.11%

Why do I need it? Cystine crystals can deposit in the cornea. This can feel uncomfortable and make you sensitive to bright lights. If left untreated it can affect your vision. Eye drops are the only way to dissolve the cystine crystals in your eye.

Possible side effects: Application may slightly sting when you first start using the eye drops.

Medication: Levothyroxine

Brand names: Eltroxin® 50mcg, 100mcg (round, white/off white colour)
Evotrox® 50mcg, 100mcg (liquid solution)

Why do I need it? Cystinosis can cause the thyroid gland to not produce enough thyroid hormone (hypothyroidism) which can cause weight gain, depression, joint pain, muscle cramps, and low heart rate. This can be treated by taking Levothyroxine.

Possible side effects: Side effects can include diarrhoea, vomiting, headaches, palpitations and restlessness.

Carnitine

Brand names: Carnitor® (oral liquid)

Why do I need it? Carnitine is used by your body to help make energy from fat. Patients with cystinosis have low Carnitine levels because it is lost in the urine.

Possible side effects: Nausea, vomiting, abdominal pain and diarrhoea. These side effects can be related to the dose you are taking. Your tolerance should be monitored during the first week and after any dose increase.

Proton pump inhibitors (PPI)

Lansoprazole, Omeprazole (capsule)

PPIs can help reduce some of the gastro-intestinal discomfort that is associated with taking cysteamine tablets.

They are generally well tolerated but some patients can experience nausea, abdominal pain, diarrhoea, flatulence and constipation.

Supplements (Various)

Brand names: Potassium, Sodium, Bicarbonate, Phosphate, Vitamin D

Why do I need it? You may need to take additional supplements to replace any important electrolytes or vitamins that your kidney wastes. The type of supplements and the dose you take will depend on your blood results.

Possible side effects: Side effects can vary greatly between patients. If you feel like you are experiencing any side effects when taking supplements you should speak to a healthcare professional.

Medication: Insulin replacement

Why might I need it? Patients with cystinosis are at an increased risk of getting diabetes. There are many different types of insulin replacement treatments available which should be discussed with your diabetic team.

Transplant specific medication

If you have received a kidney transplant you may come across the following medication. If you would like further information about transplantation we encourage you to speak to your local transplant team.

Medication: Tacrolimus

Brand names: Prograf®, Advagraf®

Why do I need it? If you've had a transplant this medication stops the body attacking the new kidney. Seek further advice from your transplant team.

Possible side effects: Side effects can include tremors, nausea, blurred vision, sleep problems. This medication will also reduce your natural defences against infection. Seek advice from your transplant team if you are experiencing any problems.

Medication: Cyclosporine

Brand names: Neoral®, Sandimmun®, Deximune®

Why do I need it? This is another medication used to stop the body attacking a transplanted kidney. Seek further advice from your transplant team.

Possible side effects: Side effects include tremors, nausea, increased hair growth, swollen gums, and numbness or tingling in your feet, hands or face. This medication will also reduce your natural defences against infection. Seek advice from your transplant team if you are experiencing any problems.

Medication: Azathioprine

Azathioprine, Imuran®

Why do I need it? This reduces the amount of white blood cells that can attack the transplanted kidney.

Possible side effects: Side effects may include nausea, vomiting, diarrhoea, fever and rash. This medication will reduce your natural defences against infection. Seek advice from your transplant team if you are experiencing any problems.

****IMPORTANT****

If you have any concerns with your medication it is important to discuss this with a healthcare professional. If you are regularly missing doses you need to inform your doctor.