MARCH 2025

myrenalnutrition.com

NEWSLETTER

News, stories hints & tips

for children with kidney disease and their families

WHAT'S INSIDE...

Vitaflo™
Enhancing Lives Together
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My Renal Nutrition
NEWSLETTER

Welcome to the seventh edition of the myrenalnutrition newsletter - a newsletter devised by Vitaflo™ for children with kidney disease and their family, with content written by individuals who have personal experiences of living with kidney disease as well as healthcare professionals who work alongside patients with this condition.

In this edition of the newsletter you will find information about dialysis, including one persons experience of having dialysis. There is also information regarding how to follow a low potassium diet and tips which may help with remembering to take medications and oral nutritional supplements. You will also find a tasty recipe idea and a fun game to try.

If you have a story to share or even a great recipe idea, please let your dietitian know and we can be sure to include it in future newsletters.

Yours sincerely

The team at Vitaflo

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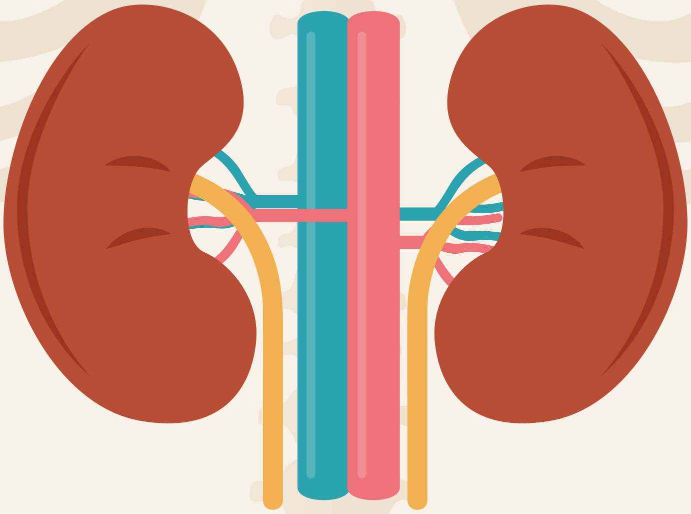
WHAT'S INSIDE...

WHAT ARE THE KIDNEYS AND WHAT DO THEY DO?

The kidneys are next to your backbone, below your bottom rib, and are closer to the back than the front of your body. They are each about the size of your fist.The kidneys have about a million little 'power-houses' that do all the work called nephrons.

The nephrons filter water and waste products which means that anything that our bodies don't need is removed. The waste is removed in the urine.

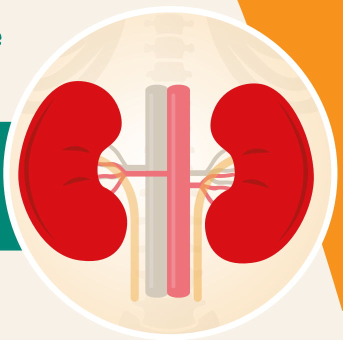
If a person's kidneys stop working or work much less than they should do, dialysis may be needed.



WHAT IS DIALYSIS?

Dialysis is the artificial replacement of kidney function, where waste products and excess fluid from the blood are removed. Dialysis can help prevent a build-up of dangerous toxins in the body for those individuals whose kidneys are not working well.

Dialysis aims to try to filter the waste from the blood the way that the kidneys do.



THERE ARE TWO TYPES OF DIALYSIS:
HAEMODIALYSIS AND PERITONEAL DIALYSIS

WHAT IS HAEMODIALYSIS?

Haemodialysis filters blood through a dialysis machine; the blood passes through a series of tiny tubes. These tubes have a specific membrane which allows harmful substances and excess fluid to be pumped through it. A clear fluid called 'dialysate' is pumped in the opposite direction to the blood flow (outside the tiny tubes) whereby the waste products enter the dialysate and are then forced out of the dialysis machine and drained away. The blood which entered the machine through the tiny tubes, is now clean and free of toxins and is ready to be re-entered back into the body.

Haemodialysis treatment usually occurs around 3 times a week, with each session lasting about 4 hours. You can have your treatment set up at home but most patients go to a dialysis centre in the hospital.

WHAT IS NOCTURNAL HAEMODIALYSIS?

Nocturnal haemodialysis or NHD, is when haemodialysis is performed overnight either at home or in hospital. It allows you to sleep whilst having the treatment, freeing up more time during the day.

WHAT IS CONTINUOUS AMBULATORY PERITONEAL DIALYSIS (CAPD)?

Peritoneal dialysis is the another type of dialysis which works by cleaning the blood inside the body. Instead of using an external machine to cleanse your blood, your body does this itself. To access the blood, peritoneal dialysis uses a soft tube called a 'catheter' which is inserted into the abdomen as opposed to haemodialysis which uses a needle. A special membrane called the 'peritoneum' lines the abdomen and acts as a filter for unwanted harmful substances and excess fluid. Throughout the peritoneal dialysis, the dialysate (which is held in a clear plastic bag above head height) enters the abdomen through the catheter. It sits there for 4-6 hours whilst the harmful substances and excess fluid are transferred into the dialysate from many tiny blood vessels called 'capillaries'. Once this is complete, the dialysate drains back out of the body through the catheter and into a waste bag.

Peritoneal dialysis is mostly completed at home with each dialysis session or 'exchange' lasting approximately 40 minutes. These exchanges will be repeated 4-5 times a day.

MY EXPERIENCE OF DIALYSIS

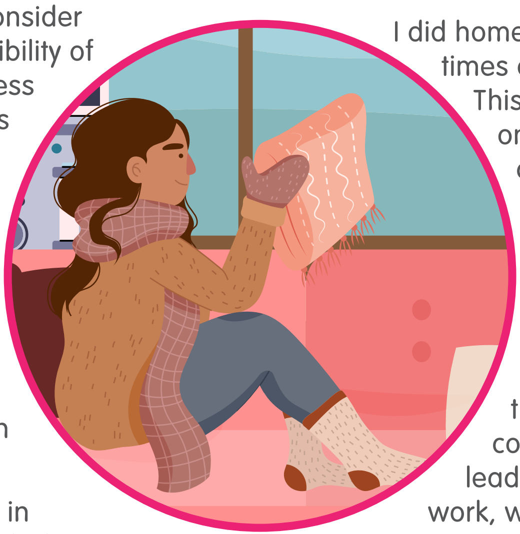
by Aphria

Aphria was diagnosed with congenital nephrotic syndrome at one year of age. Congenital nephrotic syndrome is a kidney condition that begins in infancy and typically leads to irreversible kidney failure by early childhood. Both her kidneys were removed at 18 months old, and she was on dialysis until receiving a kidney from her dad.

The kidney began failing when she was 17 years old, and after being on dialysis again, Aphria has just received her second successful kidney transplant.

Here Aphria shares her experience of dialysis.

With kidney failure being a long process and me being sensitive to medication and symptomatic for a long time, the build up to dialysis was a lengthy one; and looking back now I wish I had started dialysis much earlier. I think this is something to consider when talking about the possibility of dialysis – having an awareness that you don't have to always settle for feeling sick and that dialysis may in fact help alleviate symptoms, rather than just feeling like you are 'supposed to feel this way' and waiting for dialysis to be brought up some time down the line. It's always a good discussion to have with your team!



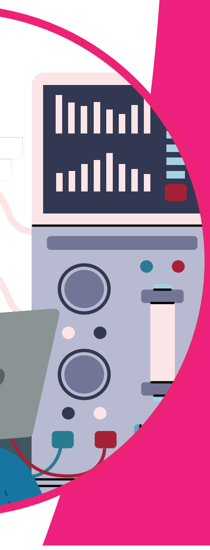
Dialysis was often discussed in terms of its limitations instead of its potential to improve a patient's quality of life. I went into kidney failure in my first year of undergraduate study and started dialysis in my fourth and final year at university. I began dialysis in the November before COVID- 19. This meant I spent a year having haemodialysis three times a week in the unit before being trained for home haemodialysis (HHD). Fortunately I was stable enough for this step and isolating at home was more comfortable than doing this in the hospital.

I did home haemodialysis (HHD) 5 to 6 times a week for around 2.5 hours. This pattern was less of a stress on my body, allowing me to come off of multiple daily antihypertensives. Dialysis can make you so cold! So my biggest tip is to definitely have a good blanket and fluffy sock collection – do not be afraid to bring anything that will make you cosy and comfortable. Also, an extension lead is useful so you can do work, watch films etc (also a good tip for any hospital stays)!! This regime really meant I could tailor treatment around my life rather than my life around the treatment, which helped in the management of the condition.

There were of course complications and the worries or concerns you have at the time can be focused on fluid, being overloaded and feeling sick for example. Hospital appointments and visits were very regular (weekly, if not more), and hospital appointments are a constant throughout all stages of CKD and post transplant. Access was an ongoing conversation as I had a line - always be open to having these discussions during your treatment, time is a big factor in the decision-making process, particularly when evaluating risk.

Learning what time of day dialysis works best for you is also key. For example, morning dialysis would make me unwell and limit my quality of life; I would get migraines and be sick for the rest of the day and then tired the next day. Whereas dialysis after midday worked better for me and made it much more manageable. Of course some days I didn't respond as well as others but the good days definitely outweighed the more sickly (bad) days. For instance, having dialysis improved my appetite slightly and made me feel better, improving my quality of life and making life seem more manageable alongside the treatment.

A special aspect of having haemodialysis in a unit is the people you meet and how 'bonded' you can become to each other; I met people from all works of life and of different ages, all needing the same treatment for one reason or another. The sort of bond that gives an odd sense of unity amongst all the changes going on around you, and a moment of calm.



The people I met throughout any of the units I went to were so welcoming and supportive, and hearing their stories and conversations really did give a silver lining on those more tiring days and most importantly, perspective that you really are not alone in all of it.

I also managed to go away on a family holiday where we were able to book into another unit for treatment. This gave a huge sense of normality and change in a time when it was hard to differentiate between the days at times. I would really recommend this if you are able as the change in scenery helps!

A difficult relationship, or certainly one that may need more care and attention is the one between food and fluid. The nature of the treatment comes with constant weight recordings and hyper awareness of how your body feels, in terms of swelling for example. It can be difficult not to fixate on this, and therefore ensuring you are not dry by eating and drinking is important, and remembering food and fluids, although having to be consumed differently than normal, are important to maintain your health and strength during treatment. You don't want to dry yourself out completely!

Fortunately, my transplant was successful and so did not need to go back onto dialysis post-transplant. I am now 2 years post-transplant and have hospital appointments every 3 months with the renal team!

WHAT IS A LOW POTASSIUM DIET?

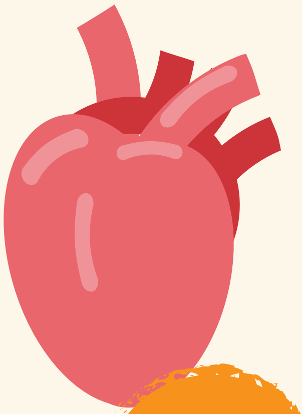
You may have been told by your medical team that you need to follow a low potassium diet. **But, what is a low potassium diet? Let's start with the basics!**

What is potassium?

Potassium is a mineral. Minerals are found in foods. Potassium is a special type of mineral called an electrolyte. Electrolytes like potassium help to keep things in balance in your body.

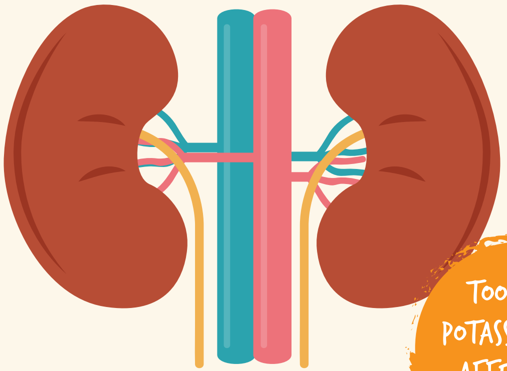
Potassium does lots of jobs in the body including:

1. Making sure the right amount of water is in the body.
2. Helping the heart to work properly.
3. Ensuring our bodies use energy and protein.
4. Making sure the right amount of acid is in the body.



POTASSIUM HELPS MAKE THE HEART WORK

What happens when the kidneys are not working very well?



TOO MUCH POTASSIUM CAN AFFECT THE HEART

The kidneys will usually get rid of any extra potassium that we don't need. However, when the kidneys are not working well, too much potassium may be left in the body.

This can affect the heart and therefore it may be important to limit the number of foods and drinks that you have which contain a lot of potassium.

1. REDUCE YOUR INTAKE OF POTASSIUM ADDITIVES

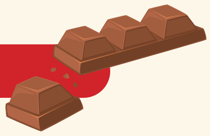
Food manufacturers sometimes use potassium containing additives in processed foods. This can mean processed foods often contain more potassium than fresh foods. Therefore, try to make meals using fresh ingredients whenever possible.

Ask your Dietitian for the potassium additive detective card to help you find which foods and drinks contain potassium additives and thus should be avoided.

2. REDUCE YOUR INTAKE OF FOODS WHICH CONTAIN A LOT OF POTASSIUM

The following foods and drinks have high amounts of potassium in them and should be avoided.

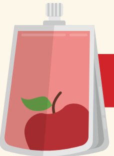
- Potato products such as chips, potato waffles and crisps



- Chocolate

- Coffee

- Ice cream



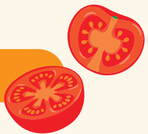
- Fresh fruit and vegetable juices

- Canned vegetable soup

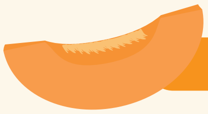
The following foods are also high in potassium and may need to be eaten in smaller amounts. Please follow the advice your Dietitian provides regarding which food and drinks you need to cut down on.

- Meat, chicken, fish and eggs

- Milk, yogurt and fromage frais



- Tomatoes and tomato products such as tomato puree

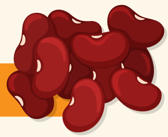


- Watermelon, honeydew melon and cantaloupe melon

- Bananas, apricots and avacado

- Spinach
- Sweet potatoes

- Dried fruits and nuts



- Beans, chickpeas and lentils

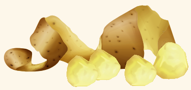
✓ The following foods contain less potassium. You could try these instead of the high potassium foods listed on the previous page:

- Rice, bread, pasta, noodles and couscous
- Cornflakes, rice krispies, wheat biscuits and wheat squares
- Cucumber, celery, green peppers and onions
- Apples, pears, tangerines and blueberries
- A small handful of raspberries
- Corn based crisps and unsalted popcorn
- Plain sponge cake, swiss roll, jam tart and treacle tart
- Plain biscuits, jam biscuits and wafers
- Jelly
- Water, lemonade and cordials

What else can I do to reduce my potassium intake?

The way we cook our food can sometimes affect the potassium content of that food or meal. Here are some low potassium cooking tips:

✓ • boil all vegetables rather than using a steamer, microwave or pressure cooker.



✓ • peel potatoes and cut into small pieces before boiling.

✗ • do not use the vegetable water to make soups or gravy (as it will be rich in potassium).

✗ • avoid salt substitutes as they contain potassium.

My low potassium meal plan

For my breakfast I can choose:

For my mid-morning snack I can choose:

For my lunch I can choose:

For my mid-afternoon snack I can choose:

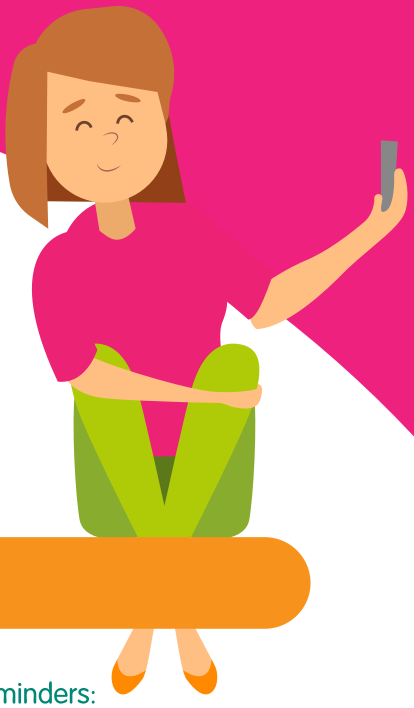
For my evening meal I can choose:

My drinks throughout the day:

Always check with your Dietitian regarding which foods you can have and which foods you should limit in your diet. Everyone's needs are different.

For more information ask your Dietitian for the **'Following a low potassium diet'** booklet by the Paediatric Renal Nutrition Taskforce

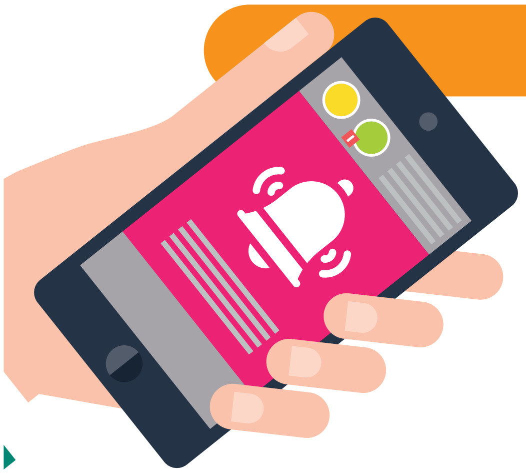
TIPS FOR REMEMBERING TO TAKE YOUR MEDICATIONS...



Nobody means to miss taking their medications or nutritional supplements but sometimes it can happen, especially when you have a lot to take at different times during the day.

Planning ahead and having a routine can help.

Remember, your medications and supplements are important and help to keep you healthy.



REMINDERS

Here are some ideas for reminders:

- Text messages – use a service for text messaging reminders at usual medication and supplement times or see if your medical team has an option for messaging.
- Set up your phone or use an app for daily alarms at your usual medication and supplement times.
- Enlist a buddy – a family member or friend to double check to see if you have remembered your medications and nutritional supplements.

MAKING IT EASY

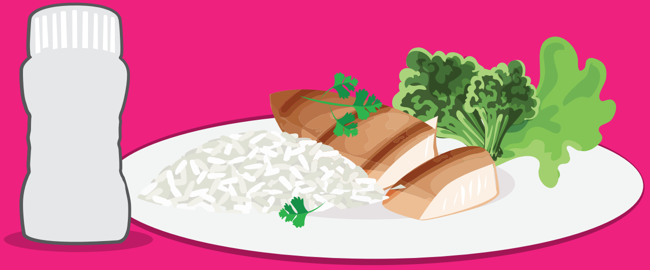
Here are some tips to make taking medications as easy as possible:

- Keep your medications where you need them. For example, if you take them at bedtime, have them next to your toothbrush, or if you take them with your meals, keep them at your spot at the dinner table.
- Keep medications handy when "on the go." Some medications, like phosphate binders need to be taken when you eat food. So keeping a small amount in your bag or in the car can help to ensure you have them at the times when you need to take them.
- Use a medication box, coin purse or other fashionable or discreet container to keep your medications handy for when you go out.

Always keep your medications in a handy place but ensure they are kept out of reach of young children.

... AND ORAL NUTRITIONAL SUPPLEMENTS

ORAL NUTRITIONAL SUPPLEMENT DRINKS



Here are some ideas which may help you to remember to take your oral nutritional supplement drinks:

- Plan to take your nutrition drinks as part of your schedule; a planned daily snack or part of your fluid restriction with a meal.
- Enjoy your supplement – make a shake or fun beverage using your supplement and other permitted ingredients such as syrups and milkshake powders.

PLAN FOR SUCCESS

Find ways to make your medication and supplement schedule easier:

- Ask your medical team which medications and/or supplements can be taken at the same time.
- Find times that are easiest to take your medications or supplements. You can talk to your team about adjusting your medication schedule slightly if needed.

Bean Burger

Ingredients

Makes
4
burgers

Makes
4
portions of sauce

Bean burger

425g canned chickpeas
4 spring onions
1 large egg
2 tablespoons all-purpose flour
1 teaspoon dried oregano
½ teaspoon ground cumin
2 tablespoons olive oil
2 pitta bread

Optional garnish:

red onion, sliced (approx 4 slices)
4 lettuce leaves, shredded
cucumber (approx 3 slices)

Bean burger sauce

½ small cucumber
240g plain Greek yogurt
¼ teaspoon garlic powder
½ teaspoon dried dill
¼ teaspoon black pepper
1 tablespoon lemon juice

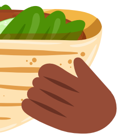
Method

Preparation for the Bean Burger Sauce

1. Wash the cucumber and grate using the large holes of a box grater. Drain off the excess liquid.
2. Mix the cucumber with the Greek yogurt, garlic powder, dill, pepper and lemon juice to make the bean sauce.
3. Cover and place in the refrigerator until ready to serve.

Preparation for the Bean Burger

1. Rinse and drain the tinned chickpeas. Chop the ends off the spring onions.
2. Using a food processor, combine the chickpeas, spring onions, egg, flour, oregano and cumin. Blend and pulse until a mixture forms that holds together when pressed. The mixture will be moist. Form into 4 burgers.
3. Heat the olive oil in a frying pan over a medium heat. When hot, add the burgers. Cook until golden and beginning to crisp (approximately 4-5 minutes). Flip and cook until golden brown and crisp (approximately 2-4 minutes more).
4. Warm the pitta bread and cut each in half.
5. Assemble your plate with the pitta half, bean burger and sauce. Add some red onion slices, shredded lettuce and sliced cucumber for the garnish.



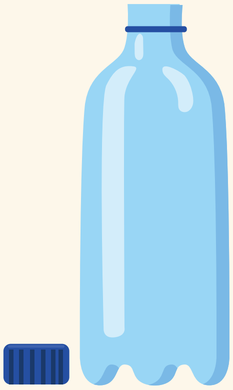
Please check with your Dietitian or Doctor that this recipe is suitable for you.

CREATE YOUR OWN 10 PIN BOWLING GAME

YOU WILL NEED:
- 10 PLASTIC BOTTLES ✓
- COLOURED PAPER ✓
- TAPE ✓
- SAND, PEBBLES OR RICE ✓
- BALL ✓

Who doesn't love a game of 10 pin bowling? Enjoy this homemade version with all the family.

STEP 1.

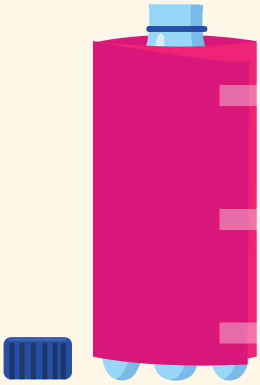


TIP: Make sure your 10 plastic bottles are all the same size.

Find 10 plastic bottles. Remove any outer packaging and plastic wraps. Remove the caps and clean the bottles thoroughly.

STEP 2.

TIP: Use different coloured paper for each bottle.



Wrap coloured paper around the bottle and fix with some tape.

STEP 3.

TIP: If you don't have sand, you could use small pebbles, rice or water to provide stability to the bottle.

Add a small amount of sand into the bottles. This will make the bottles heavy and make them stand up strong. Then put the caps back on the bottles.

STEP 4.

Set up your bowling pins,
grab a ball and have fun!

THE RULES OF THE GAME:

A game consists of 10 frames and each bowler is allowed to roll the ball twice in each frame to attempt to knock down all the pins.

One point is scored for each pin that is knocked over. If a bowler is able to knock down all ten pins with their first ball, they are awarded a strike.

If the bowler is able to knock down all 10 pins with the two balls of a frame, it is known as a spare.

Keep a pen and paper handy to make a note of the players scores. The winner is the player who scores the highest after all 10 frames.

Vitaflo (International) Ltd is a clinical nutrition company who specialise in developing products and resources for those with kidney disease. The information in this newsletter is for general information only and must not be used as a substitute for professional medical advice or treatment. Your dietitian and doctor will provide you with advice with regards to the management of your condition and it is important that you follow the advice that they provide.

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Vitaflo™

Enhancing Lives Together

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